DESIGNING COLLABORATIVE MOBILE HEALTH EXPERIENCES FOR ADOLESCENT PATIENTS

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DESIGNING COLLABORATIVE MOBILE HEALTH EXPERIENCES FOR ADOLESCENT PATIENTS

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This dissertation is lovingly dedicated to my wife, Karen Kang, for her encouragement, patience, and continued support while I worked toward completing the PhD program.

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SUMMARY

The proliferation of patient-generated data and mobile health (mHealth) technologies has provided unprecedented opportunities for patients' everyday health management and active participation in health care. Designing and introducing personally-collected mobile data into pediatric patients' everyday health management tasks, however, brings unique challenges for computing research. These patients will need to collaborate with family and clinical caregivers to successfully manage their care, yet they struggle to articulate their needs and face many barriers that affect their participation in care.

My research focuses on the design of collaborative health management tools for adolescent patients (ages 10–19) in onco-hematology and rheumatology settings. It includes a series of qualitative and formative design studies involving patients, family members, and clinicians, to formulate design requirements for mHealth tools for illness documentation, communication, and management. This dissertation describes several completed studies organized under three themes. My early formative work provides an overview of the problem and design space for patient participation in complex chronic care, which informed my decision to focus on tracking illness experiences. Through two collaborative design studies, I characterized patient-defined, patient-generated health data for illness communication, by engaging with patient-parent dyads and clinical professionals. Finally, I describe a long-term probe study and design of a mHealth technology to gain an in-depth understanding of how technology can be designed to support patient-authored illness narratives based on experiential data collaboratively generated by patients and their family caregivers.

This research contributes: 1) a critical understanding of the ways that human-centered design can address the primary challenges that adolescent patients face when engaging in complex chronic care management, and 2) design guidelines and artifacts that can inform new tools to support families' collaborative documentation and communication of patient-generated health data in pediatric care.

CHAPTER 1
INTRODUCTION

In pediatric care for complex chronic conditions, effective communication among pediatric patients, family caregivers and clinicians plays a fundamental role in determining the patient's quality of life and satisfaction with care [1, 2, 3]. Patients' ongoing awareness of their health status and ability to articulate health needs are vital to communication and active participation in care, yet adolescent patients face various challenges that could thwart their potential to engage in such participation. Meaningful Use guidelines for Electronic Health Records (EHRs), enabled through the HITECH[1] Act of 2009, allow patients to have increased electronic access to their health data generated during clinical visits. In a pediatric chronic care setting, decisions about treatment and supportive care are made based on a comprehensive understanding of the patient's health data, which comprise a combination of assessments, including diagnostic physiological data, physician's global assessment, and caregiver-reported observations of the patient's health status [5]. While patients have the first-hand experience of various signs of illness (e.g., treatment-induced symptoms), there is little consideration for patients' own assessments of their health (or patient-generated health data) in clinical decision-making, due to their dependence on family and clinical caregivers and lack of means to understand and express their health needs. This suggests an opportunity for technology to play a role in supporting adolescent patients' illness management by **fostering a meaningful understanding of their own health** through **collaborative partnerships with family caregivers**.

[1]The Health Information Technology for Economic and Clinical Health [4]

1.1 Thesis Statement and Research Questions

My research addresses how we can design for and with adolescent pediatric patients through a unique combination of methods that collaboratively engages them in 1) defining the design space, 2) characterizing the design artifacts for eliciting illness narratives, and 3) generating insights to inform the design of a mobile health technology that aims to support their everyday health management needs.

In particular, this dissertation demonstrates that, we can engage these patients in their own care by *providing age-appropriate, relatable, and personalizable representations of health data* upon which they can build, to articulate their health status. We can promote patients' gradually-evolving partnerships with family caregivers by *providing individual mobile health experiences that allow for both personal use and collaborative reconciliation of illness observations*.

Three research questions guide my work:

RQ 1: What challenges and opportunities shape the design space of patient engagement in care processes for adolescents and family caregivers?

RQ 2: How can we elicit information about adolescents' illness experiences to create illness representations that are meaningful to them and their family members?

RQ 3: How can we design computing technology to engage adolescents and their family members in everyday health management?

In order to address these questions, my research applies the following methods: participant observations, interviews with individuals, surveys, portal usage log analysis, co-design, diary and probe study, and prototyping and user testing. My work contributes empirical findings, methodological innovations, and design artifacts that together lay the foundations for the design of a robust technology application and study protocol for a subsequent, large-scale study on adolescent engagement. Table 1.1 summarizes these studies.

Table 1.1: Summary of Studies. S(n)=Study Number; PS=Pilot Study.

Theme	**Studies**	**Dates**	**Status (Venue)**	**Data Sources**	**Study Specific Research Questions**
Understanding Participation in Care of Complex Chronic Conditions	Care Partners (S1)	Oct. 2014 - May. 2015	Completed (CHI2016)	Semi-structured interviews, participant observation	What barriers do adolescents face in their engagement in patient-doctor encounters, and how can technology help them overcome such barriers?
	MyChart PHR (S2)	Aug. 2014 - Feb. 2016	Completed (AMIA2016)	Semi-structured interviews, portal usage logs (9 mos.), survey of portal users	Does the use of a tethered PHR system (when it is available), influence adolescent and parents' participation in care?
Characterizing Patient-Defined PGHD	Visual ODLs (S3)	Mar. 2017 - Aug. 2017	Completed (CHI2018)	Semi-structured interviews, co-design	How can we elicit various representations of patients' everyday illness experience?
	Integrating ODLs in Care (S4)	Oct. 2017 - Dec. 2017	Completed (ICHI2018)	Semi-structured interviews	How do clinicians prefer to integrate PGHD (vODLs) into their own practice?
Supporting Design Work In Everyday Life	Diary Probe (S5)	Aug. 2018 - Feb. 2019	Completed (CHI2020)	Paper diary, probe, pre/post surveys, semi-structured interviews	In what ways do adolescents and parents prefer to capture, express, and communicate about the patient's illness experience?
	mHealth Probe (PS)	Aug. 2019 - Oct. 2019	Pilot	Mobile ecological momentary assessment, surveys, semi-structured interviews	Will patients (engaged in their daily design process) become confident in their ability to manage and articulate their illness experience?

1.2 Research Narrative

Guided by the three research questions above, I organized all completed research studies under three large research themes that uniquely address these questions. I describe these themes and summarize relevant research findings below.

1.2.1 Understanding Patient Participation in Complex Care

From 2014 to 2016, I partnered with care providers at CHOA's Cancer and Blood Disorders Center to conduct a two-year investigation of chronically-ill adolescent patients' and family caregivers' to provide an in-depth characterization of the current state of adolescents' engagement and participation in the clinical setting.

What barriers do adolescents face in their engagement in care? How can technology help them overcome such barriers? In addressing these questions, my formative work surfaced nuanced implications of adolescent and parent engagement in care by synthesizing diverse perspectives from many stakeholders, including patients, parental caregivers, and clinical caregivers as well as child-life specialists.

Through observations of consultations and semi-structured interviews (conducted individually and in private) with patients, their parents, and the oncology team at CHOA, I learned that adolescents faced challenges participating in clinical conversations due to previous experiences with explanations that they could not understand, and having very little expectations that they will receive a comprehensive answer. I also learned that adolescents faced challenges in recognizing and reporting physical and emotional responses due to the burden that came with physical ramifications of the illness as well as having discordant observations with their parental caregivers. In particular, while patients downplayed their symptoms not to worry their parents, symptom reporting was often assumed by parental caregivers—even if the reported data may not adequately represent the patient's true felt experience.

These findings prompted me to conduct the first study reporting on adolescent and parent perspectives after observing their use of a tethered personal health records system, CHOA MyChart, during a 19-month period. I, however, found that current patient portal technologies had limited means to engage these patients in care.

This line of work illustrates the care that went into understanding the delicate tensions between patients' struggle for personal autonomy and parents' desire to understand their child's health status and access their records. For example, I was able to uncover these tensions by orchestrating simultaneous, yet private interviews with patients and their parental caregivers, thereby ensuring patients an extra layer of confidentiality.

By synthesizing multiple perspectives on patient participation in care, I was able to characterize the design space for accommodating patient and parent perspectives. The nuance is the need for both increased independence as an adolescent coupled with the dependency that the disease places on them. I concluded that patients need help recognizing the ever-changing, and often unpredictable, signs of illness. To do this well, they inevitably need to collaborate with family caregivers to document their illness narratives in the context of everyday living.

1.2.2 Characterizing Patient-Generated Data with Co-Design

While Studies 1 and 2 provided an overview of the design space for adolescent participation in care, Studies 3 and 4 focus on characterizing patient-defined patient-generated health data (PGHD), and generating the necessary design artifacts that comprise a central piece in the design of a mobile health system. To communicate their illness needs, adolescents will need to build upon meaningful representations of illness experiences.

How can we better elicit adolescents' illness experiences? What does it mean to create meaningful representations? In addressing these questions, I discovered collaborative design (co-design), which is a powerful design method that democratizes the design process by directly involving the intended users as co-partners to envision and conceive of a tech-

nology design through multiple design activities. Concurrently, I also became aware of the positive impact of images on illness communication.

In Study 3, I used co-design as a primary method to explore and characterize meaningful representations of the patient's illness experience. Through storyboard-based co-design with patient families, I found the right set of building blocks, or visual observations of daily living (ODLs), to help young patients recognize (rather than recall) what they were going through, and enable them to contribute new designs that better represented their personal experiences. In this way, they were aided by visual ODLs, but also played a direct role as designers in crafting meaningful representations of their illness experiences.

In a qualitative exploration (Study 4) with clinicians in an onco-hematology setting, I found that clinicians often face the burden of reconciling conflicting perspectives among patients and family caregivers. In specific, they promoted patient-initiated, first-person illness narratives during face-to-face encounters, and valued a summarized view of the patient's illness experience between visits that highlights concerning symptoms by presenting symptom attributes in the order of highest frequency, severity and interference with specific daily activities.

These studies allowed me to distill three important design goals to support patient narratives of their daily experiences during treatment: to allow full expression of how symptoms affect patients' daily activities, use of various media data representations (e.g., photo, drawing), and support distinct roles for family caregivers to contribute their unique observations of the patient experience. These goals informed the design of the current mobile health (mHealth) system.

1.2.3 Supporting Situated Design Work in Everyday Life

My ultimate goal for this dissertation is to understand how to design computing technology to engage adolescents and their family members in everyday health management. Evidence from my prior studies suggest one potential direction to address this goal: families

can work together to co-construct patients' illness narratives in everyday life. It is now possible to tap into adolescents' high engagement, literacy and familiarity with media tools, to help them construct rich narratives of their daily illness experiences—powered by a suit of media technology that are readily accessible through personal mobile devices. To do this, I employed ecological momentary assessment (EMA) methods that are geared towards achieving high ecological validity by placing the data collection activities in the hands of patients and their parental caregivers, in their natural setting.

In a two-week diary probe study (Study 5) that draws on lessons from Study 3, young patients were able to develop treatment-specific health literacy in the act of diary-based documentation, contextualize documented experiences by engaging with media probes (a variant of Hutchinson's Technology Probes [6]), and coordinate the exchange of emotionally-sensitive signs of illness with their parents outside of the typical context of face-to-face communication. These findings directly provided design guidelines and goals that inform the design of a mobile health (mHealth) application, including the interactions needed to support family management of chronic conditions.

mHealth technology opens up opportunities to provide a more objective account of health behaviors and experiences that can lead to higher accuracy, improved patient–clinician communication and care planning. In a pilot study (PS), I deployed a fully functional mHealth tablet application in family home settings to explore novel automated and semi-automated strategies for eliciting collaboratively-generated observations of patient activities and illness experiences.

1.3 Overview of Dissertation

The rest of the dissertation is organized as follows: in Chapter Two, I provide the specific design context for my dissertation and the approach I take in addressing the relevant computing challenges. In Chapter Three, I review relevant background literature on illness narratives, barriers to patients' engagement in care and patient-generated data. Chapter

Four reviews two empirical studies that I conducted to define the design space of chronic illness care for adolescent patients and family caregivers. Chapter Five reviews two formative design studies that address ways to characterize PGHD from the perspective of adolescent patients and clinicians. In Chapter Six, I describe a diary study that explores the intersection of tracking and probes to support patients' and families' construction of illness representations for clinical communication. In Chapter Seven, I outline a set of design guidelines and design goals specific to my research that I distilled from the five completed studies. Chapter Eight describes the design process and features of the CO-OP mobile health system that draw from prior studies, and preliminary findings from a pilot deployment study. I discuss the implications for design and opportunities for future work in Chapter Nine, and conclude the dissertation in Chapter Ten with contributions to HCI research.

CHAPTER 2
DESIGN CONTEXT + APPROACH

In this section, I first introduce the specific context within pediatric care in which I conduct various research activities to design for adolescent patients. I then discuss major computing challenges of designing for the adolescent population. Finally, I introduce three primary approaches that I employ in my research and elaborate on their significance with respect to addressing the computing challenges that I set forth.

2.1 Design Context

2.1.1 Complex Chronic Illness in Pediatric Care

Complex chronic conditions (CCC), as defined in clinical studies based on ICD-9 diagnosis codes, include a range of diseases that "*can be reasonably expected to last at least 12 months and to involve either several different organ systems or one system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center*" [7]. By this definition, CCCs are different from more prevalent forms of pediatric chronic illnesses such as asthma, obesity and diabetes [8].

Pediatric cancer and lupus, which are the focus of my work, fall under the definition of CCCs based on the characterization of specific diagnosis codes that match malignancy and immunologic disease categories (see Appendix B.1). Although not prevalent nationwide, cancer is known to cause high mortality rates among pediatric patients—only to be surpassed by accidents [9]. In 2017, an estimated 15,270 children and adolescents (ages 0 to 19 years) were diagnosed with cancer, and 1,790 died of the disease in the United States [10]. Systemic Lupus Erythematosus (SLE), or Lupus, is a type of rheumatic autoimmune disease—estimated to affect 5000 to 10,000 children every year [11]. Lupus is commonly

treated with a mix of anti-inflammatory, cortico-steroid drugs or immunosuppressants.

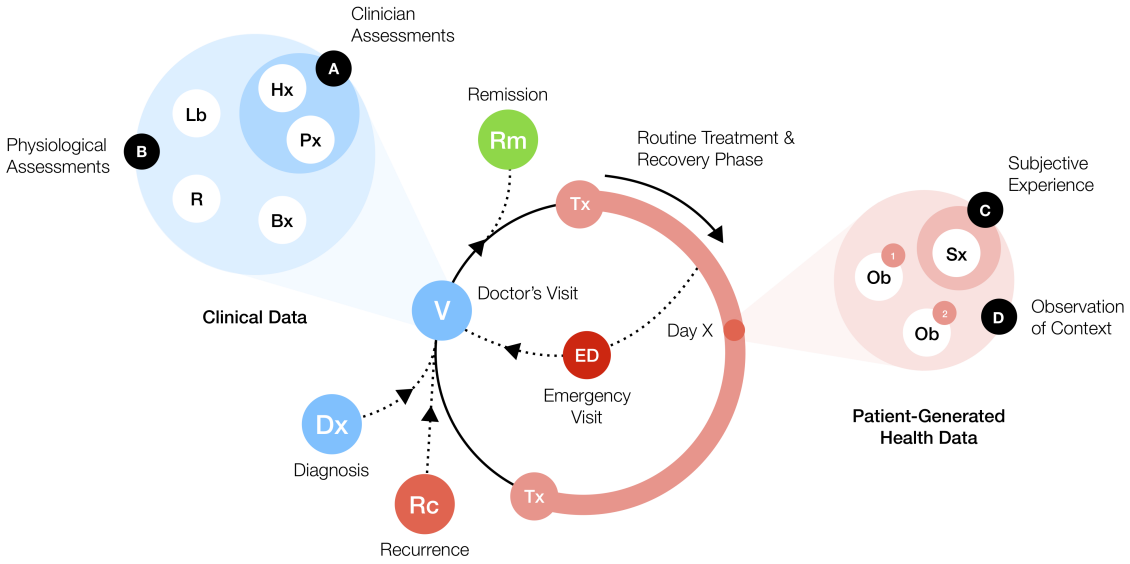

Figure 2.1: Illustrative Example of Chronic Care Cycle in Routine Treatment of CCC. Clinical data comprises a combination of physician-reported global assessments (A; Hx=History Taking, Px=Physical Exam) and clinically obtained physiological assessments (B; Lb=Lab Test, R=Radiology Exam, Bx=Biopsy). PGHD comprises patient-reported subjective experience of illness symptoms (C; Sx=Signs and Symptoms) and related observations (D; Ob=Observations) that provide the context for each experience.

Treatment as Cycles in Care of Complex Chronic Illnesses

Once diagnosis is confirmed, treatment for cancer and lupus is expected to progress in a non-linear fashion, with repeated cycles of therapy, doctor's visits, and remission or recurrence—even when patients are compliant in their therapies [12]. Treatment regimens can include frequent blood transfusions, hormonal therapy, and chemotherapy, typically requiring the need to balance effectiveness of the dosage with side effects to the patient [13]. Even when "under control" or in remission, follow-up and continued vigilance are necessary throughout one's lifetime [14].

Chemotherapy, the most prominent cancer treatment procedure, is typically administered intravenously in an inpatient setting. Chemotherapy is used with other treatments: to reduce the size of a tumor prior to surgery or radiation therapy (neoadjuvant chemotherapy),

or kill remaining cancer cells after surgery or radiation therapy (adjuvant chemotherapy). For cancer care, each chemotherapy cycle consists of an outpatient or inpatient treatment visit (lasting one to five days), followed by two to four weeks of recovery at home. Patients may receive up to 14 chemotherapy cycles according to established standards of practice and at the attending physician's discretion [15]. Treatment regimens for Lupus vary by individual patients, but usually require long-term monitoring with bi-weekly to monthly visits to the clinic.

Not all treatments for these conditions lead to positive outcomes, and the effects of chemotherapy can take a huge toll on the patient's physical, psychological, emotional, and cognitive well-being. For example, antimetabolite medicine (e.g., methotrexate)—commonly used in both cancer and lupus treatment—causes dizziness, fatigue, headache, mouth ulcers, and decreased appetite [16, 17]. Among these adverse effects, chemotherapy-induced cognitive impairments (also known as 'Chemobrain'), such as difficulty concentrating or remembering, are known to severely compromise patients' ability to track and communicate symptoms and side effects to their care team [18]. Despite these difficulties, Patel et al. found that a majority of these patients still rely on retrospective memory to report their symptomatic experiences, and argued for the benefits of real-time symptom tracking [19].

Supportive Care

Pediatric cancer care relies heavily on supportive care services due to the anticipated side effects of routine cancer treatment. While its definition is still debated, supportive care is broadly defined as the "*provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases*" (see Appendix B.2 for a detailed list of specific needs within each category) [20]. Because supportive care is not concerned with disease-specific outcomes, the goal of supportive care is to improve the quality of life for

young cancer patients and their family members [21].

In theory, 'whole person' care can be realized when the care team can meet all the supportive care needs of cancer patients [22, 23]. However, there is a large unmet need for supportive care in current pediatric cancer care practice [24, 20]. Meeting these needs requires the provision of services through various professional and volunteering partners in care, including, but not limited to, social workers, psychologists, clergy/chaplains, nutritionists, physiotherapists, occupational therapists, speech therapists, and therapists in the fields such as art, music and touch [23]. While such services are usually available in tertiary pediatric hospitals, they are mostly accessed through referrals based on clinician's global assessment of the patient's overall well-being during face-to-face encounters. There is a huge opportunity to encourage patients to more proactively seek supportive care services between visits, by facilitating their communication and expression of these needs to the care team through the proper design of health information technology.

2.2 Computing Challenges of Eliciting Health Data

According to the Pew Research Center, most adolescents are already expected to be highly receptive to electronic methods of data capture [25]. Today, 95% of adolescents own or have access to mobile phones that are equipped with media tools to capture aspects of daily life [26]. On a daily basis, young people in this population are found to spend an average of three hours a day on communication apps alone [27].

Mobile phones are easily one of the most personal communication technologies that adolescents carry in their possession, and this gives researchers an unprecedented opportunity to understand their day-to-day behavior as well as emotional and physical experiences at a granular level. Adolescents' high receptivity to mobile technologies could provide opportunities to collect health-related data and deploy digital health interventions outside of the traditional laboratory setting through mobile health (mHealth) technologies [28].

However, eliciting experiential health data effectively from individuals in everyday, nat-

uralistic contexts is an ongoing area of research. In my research, I found that adolescent patients and their parents faced significant difficulty tracking many signs of illness and reporting them to clinical caregivers. First, many side effects that patients encounter as part of their treatment (e.g., nausea, depression, etc.) are highly personal and individualized experiences, have very little visible cues for human observers, and are not amenable to passive sensing and detection. In addition, the toxic effects of treatment could compromise cognitive function, which in turn interferes with the patients' ability to express these experiences [13]. Lastly, most adolescents are still developing the necessary literacy and conversational skills required to articulate unfamiliar physical sensations and emotions [29]. These challenges have significant implications for interaction design researchers employing interview techniques that rely on verbal cues and patients' recall of illness experiences.

To tackle these challenges of eliciting health data, my research draws heavily from three complementary approaches for engaging adolescents in design: collaborative design (co-design) studies, visual storytelling, and in-situ data collection methods.

2.3 Methods for Engaging Adolescents in Design Research

Poole and Peyton stated that many researchers experience difficulty extracting insights from adolescents through qualitative open-ended questions, in part because adolescents have difficulty articulating responses [30]. In pediatric care however, designing for the adolescent patient alone does not sufficiently address the problem space. As dependents in their care, adolescent patients will need to collaborate with family and clinical caregivers to make sense of their health and reconstruct lived illness experiences for clinical communication.

2.3.1 Collaborative Design Studies

Co-design and Participatory Design methods, including interviews and participatory workshops, are often employed in formative design research with children [31]. A key tenet of co-design is to directly involve the intended users of an envisioned technology in the

design process, and to conceive of the design in an iterative fashion via multiple design activities with user–participants. What co-design can offer is a perspective that incorporates and synthesizes the unique values of patients, parental caregivers and clinicians needed for creating appropriate technology utilized in the elicitation, capture, and communication of the patients' illness experiences. As I will describe later in Chapter 3, while doctors and patients already have differing preferences for representing the illness experience, adolescents and parents have conflicting interpretations of the illness experience, which can lead to discrepant reports during doctor-patient encounters. Through co-design, we can move toward a better understanding of such tensions and barriers to effective communication between multiple stakeholders.

However, these methods present notable limitations in our domain. The presence of authority figures (i.e., researchers, parents) can discourage candid responses from adolescent participants in interviews and workshops. Including adolescents' peers in formative studies can yield higher engagement [30]. Yet, even the presence of peers can inhibit candid responses, especially regarding sensitive topics related to personal, lived experiences of illness. Furthermore, while in-person meetings offer irreplaceable value, especially for eliciting expressive feedback (e.g., arts and crafts, role-playing, etc.), coordinating these activities with ill adolescent patients often means removing them from context that is in fact vital to capture. Using retrospective methods to capture adolescents' experiences often means removing them from immediate context and relying on memory rather than actual events. Consequently, the design ideation that follows is, in part, removed from authentic experience. This tension between the need to elicit everyday experiences while acquiring personally- and contextually-relevant design feedback—directly coupled with those experiences—calls for a new method within co-design.

Recent studies explored the coupling of participants' everyday experience with design activities through a combination of diary studies and design probes. MacLeod et al., proposed the Asynchronous Remote Communities (ARC) method to engage remote, dis-

tributed patient communities in Facebook groups in a series of design activities [32]. While the ARC method was effective in assessing needs from distributed groups that are difficult to reach in person, the authors cautioned about the challenge of maintaining engagement from participants and performing coordination work required to analyze qualitative feedback coming from multiple data sources.

2.3.2 Empowering Adolescents through Visual Storytelling

Research in social sciences for health promotion consistently found that methods involving adolescents in the process of collecting data through visual means (e.g., photograph, video), then using that data to construct their own illness narrative through visual storytelling could be a powerful way of engaging adolescents with their health [33, 34, 35].

The use of media to engage adolescents in visual storytelling is a promising prospect. A recent survey of teenage adolescents reported that video content platforms (e.g., YouTube, Instagram, and Snapchat) are among the top applications they use [26], motivating research on the role of video-based methods [36, 37, 38] for design research with young patients. PhotoVoice is a photography-based qualitative research method that has been employed as a prominent means to empower underrepresented and vulnerable populations (including chronically-ill adolescent patients) to collect information about aspects of daily living to develop personal and social identities instrumental to building social competency [34, 33]. In the context of chronic illness management and clinical communication, Rich et al., developed the Video Intervention/Prevention Assessment (VIA) tool to support adolescent asthma patients' visual illness narratives through self-recorded video footage of their daily lives [37]. The research team found that, as a research and communication tool, VIA was effective in finding environmental and psycho-social factors that were not identified by standard clinical tools and aiding clinicians' understanding of counterproductive patient behaviors by showing them in context with the adolescent's experience of illness and health care. They also found that patients' overall quality of life scores improved while using VIA

[39].

While the use of these visual methods show promise for illness management in complex treatment, the collection of photo and video data for lengthy time intervals can pose significant challenges for adolescent patients and the research team. For example, Drew et al., pointed out that adolescents didn't know what to capture using researcher provided cameras due to lack of instruction, and that the research team faced the burden of processing and analyzing massive amounts of qualitative data [33]. Such challenge calls for a need to vary the representation (from abstract to concrete) of illness narratives with cautious consideration for the patient's health information needs and clinical context.

In my research, I combined the strengths of co-design and visual storytelling to engage adolescent patients in design studies. Adolescents' participation in formative studies for requirements gathering can be aided by visual prompts or material artifacts to scaffold their articulation of their illness experiences [33, 35]. Co-design techniques such as storyboarding can facilitate the process of eliciting child-led narratives and design feedback [40]. Comic-boarding [41] and fictional inquiry [42] have been used with children to scaffold the ideation process through visual illustrations that provide context and ideas from which children can extrapolate. I used storyboarding as a method to understand the patients' first-person narrative of their illness and elicited their perspectives on when and how they prefer to engage in media-based capture and expression of various illness experiences that unfold in their daily life.

2.3.3 In-situ Data Collection Methods

While co-design activities today build on participants' retrospective memory recall, this recall can be easily compromised during the memory reconstruction process without any use of concrete cues that are anchored to the actual experience [43]. In particular, recall bias is purportedly greater in patients undergoing advanced treatment such as chemotherapy [18]. When working with vulnerable patient populations who may experience cognitive

difficulties, researchers can only hope that the resulting design ideation and artifacts from co-design activities represent the actual experience with enough accuracy.

Today, mobile and ubiquitous technology can help increase researchers' confidence in the participants' ability to accurately recall moments of their past experience. In HCI research, a convincing case has been made for the use of mobile technology as a retrospective memory aid or life-logging tool, which was in part sparked by Microsoft's SenseCam[1] project. Smartphones and dedicated life-logging tools could enable peoples' ease of access to, and total recall of, episodes of their past memory when provided in digital form—as in photo and video. Yet, a decade of research in life-logging technology suggests that such tools should not focus on "total capture" to merely serve the role of storing digital archives of our memory, but facilitate *reminiscence* and *reflection* about them [45, 46, 47, 48]. As Sellen and Whittaker note, life-logging systems can support this design goal by providing strong cues[2] such as place, events, and people that trigger different memories. Such insights corroborate my prior work on characterizing ODLs [50], which build on the notion of collecting personal data about events (status or behavioral indicators) and social (people) and environmental (place) indicators.

Further advances in ubiquitous computing technology also helped accelerate methodological advances in in-situ data collection that primarily involve Ecological Momentary Assessment (EMA) or Experience Sampling methods. While the intellectual merits of certain categories of EMA methods—such as interval-, signal-, event- or context-contingent designs—have been established [51], recent methodological advances focused on exploring the design of EMA prompts in ways that reduce respondent burden while improving response accuracy, respondent motivation and data quality [52]. For example, many researchers including Intille [53] and Ashbrook [54] proposed an interaction paradigm called

[1]SenseCam is a wearable digital camera which captures an electronic record of the wearer's day by automatically recording a series of still images through its wide-angle lens, and simultaneously capturing a log of data from a number of built-in electronic sensors [44].
`https://www.microsoft.com/en-us/research/project/sensecam/`

[2]Relevant psychology research shows that contextual information such as place, events, and people are stronger cues than time when retrieving autobiographical memory [49].

'micro-interactions' and explored the use of wrist-worn devices to reduce the respondent burden. Other researchers explored mobile interaction techniques such as unlock journaling to tackle the problem of mitigating the user burden of needing to unlock their mobile phone to navigate to a specified application [55]. While these explorations provide insights into reducing user burden when responding to EMA prompts, certain EMA designs that require rich subjective responses such as mood or emotions still necessitate qualitative feedback tied to numerical rating scales [52].

The use of EMA methods in personal informatics research today have contributed to a better understanding of ways to support reflection about personal health data [56, 57]. Most prominently, recent research points to the promise of using quantitative and qualitative data as a way to contextualize the needs identification process. In the context of diabetes management, the MAHI system demonstrated the use of patient-logged blood glucose measures, photos and notes about their dieting behavior to facilitate their social interaction with diabetes educators [58]. Through MAHI, the authors found that newly diagnosed patients were able to engage in reflective thinking of past experiences in order to refine future choices. Kay et al. demonstrated the use of weight data tracked over a two week period followed by user's comprehensive data review to ground the qualitative understanding of user perspectives and needs requirement related to the bathroom scale device [59]. Kendall et al. followed with a similar study design using blood pressure data monitored over two weeks, and found that people were able to reflect on their data to make associations with stress, food, and daily routines [60]. The benefits of using participant-collected data to engage them in reflection is clear, but how to effectively leverage this data and momentary self-reporting to inform design thinking is yet to be explored.

2.4 Context of Research Activities

2.4.1 Children's Healthcare of Atlanta

Children's Healthcare of Atlanta (CHOA) is the largest pediatric provider in Georgia—and one of the largest in the country—caring for more than half a million children and adolescents every year [61]. Composed of three hospital campuses—Egleston, Scottish Rite, and Hughes Spalding—CHOA offers more than 2,000 pediatric physicians representing over 60 pediatric specialties and programs, 638 licensed beds, Marcus Autism Center, 28 neighborhood locations, including eight urgent care centers, more than 80 telemedicine locations state-wide, and a team of more than 10,600 employees and 7,000 volunteers all committed to the patients' wellbeing. Children's is ranked among the nation's top pediatric hospitals in the U.S. News & World Report 2018-2019 edition of "Best Children's Hospitals." Recognized as one of the most comprehensive listings of its kind, the report ranks hospitals for excellence in outcomes, program structure and national reputation in 10 pediatric specialty areas.

All field research activities I conduct in my work took place at two Aflac Cancer and Blood Disorders Centers (CHOA Scottish Rite and Egleston) and a rheumatology clinic (CHOA Center for Advanced Pediatrics), with each site serving different demographic populations (urban and suburban). While the clinics treat pediatric patients of all ages up to 21, my work focuses on adolescents (ages 10 to 19) and their family caregivers. Through five years of ongoing partnerships with physicians, nurses, and various clinical staff members in all clinical centers, I was able to recruit 152 research participants, including 118 patient family participants (or 59 patient-parent pairs) and 34 clinical caregivers while completing all research studies. My research has largely relied on and benefited from this continuing partnership with the care team at CHOA.

Aflac Cancer and Blood Disorders Center

Among CHOA's popular specialty care services, The Aflac Cancer and Blood Disorders Center provides advanced diagnostic and clinical care, educational programs, psychosocial support, as well as innovative treatment and research options to children and adolescents [62]. Each year, the Aflac center cares for more than 450 newly diagnosed cancer patients and sees more than 5,000 patients with sickle cell disease, hemophilia and other blood disorders. The center houses more than 640 pediatric professionals and has 64 inpatient beds.

All field research activities focusing on oncology and hematology patients took place at two Aflac Cancer and Blood Disorders Centers: Scottish Rite and Egleston. Common cancer diseases treated in the clinic include Leukemia, Lymphoma, Brain tumors, Neuroblastoma, and Bone and soft tissue sarcomas. Commonly treated blood disorders include Hemophilia, Thrombosis, Sickle cell disease, Thalassemia, and Bone marrow failure syndromes. Common types of treatment in the Aflac clinic include chemotherapy, radiotherapy, hormonal therapy and surgery, and patients' typical length of stay vary (1–5 days) depending on the type of treatment.

Center for Advanced Pediatrics

On July 24, 2018, CHOA opened the Center for Advanced Pediatrics (CAP), a 260,0000-square-foot outpatient, non-emergency facility. The new center is the only one of its kind in Georgia and brings together multiple pediatric clinics, programs and specialists under one roof. Centrally located to Egleston, Hughes Spalding and Scottish Rite hospitals, CAP houses 457 physicians and employees and has anticipated managing more than 100,000 patient visits in the year of 2018-2019. The innovative eight-floor outpatient facility provides care across more than 20 pediatric specialties, with more than 250 rooms for patient care, exams, consults and procedures. Additional building features include a café, telemedicine capabilities, conference rooms, collaborative clinical space, patient family respite areas,

mother's rooms on every floor and a teaching kitchen to enhance specific clinical programs. The center also offers imaging and lab services for quick and easy access as well as a pediatric research center providing a convenient, dedicated location for patients to participate in clinical trials.

The Rheumatology clinic is among many clinical services that recently moved into the CAP building. Common diseases treated in the Rheumatology clinic include Lupus and Juvenile Idiopathic Arthritis. Building on my existing relationship with CHOA's hematology and oncology clinical partners and the Pediatric Alliance, I have continuously reached out to several clinical directors at CHOA to expand the reach of my research to pediatric patients with complex chronic conditions. After engaging with clinicians from endocrinology, gastroenterology, rheumatology, pulmonology, nephrology and HIV, I was able to establish a solid working relationship with Pediatric Rheumatology Chief Sampath Prahalad, MD and clinical research coordinator Lori Ponder, BS, CCRP in the past two years (since summer of 2018) to facilitate Lupus patient recruitment and research activities.

2.4.2 CHOA MyChart Personal Health Record System

In Summer 2014, CHOA released MyChart[3], a secure, HIPAA-compliant, tethered PHR. I took advantage of this opportunity in the beginning of my PhD career and partnered with CHOA's Cancer and Blood Disorders Center and their IT team to conduct a two year investigation of adolescent patients' and family caregivers' attitudes and experiences with respect to their use of the MyChart PHR system.

Along with secure messaging capabilities to facilitate asynchronous electronic messaging between parents, pediatric patients and CHOA physicians, the tethered PHR (also referred to as a "patient portal") includes access to laboratory test results, medication lists, patient allergies, prescription refill functions, appointment scheduling, messaging with clinical staff and the ability to store personal data. Once registered, patients and parents are

[3] `https://mychart.choa.org/`

given separate accounts with which they can access MyChart. The portal does not (by default) provide different viewing experiences of the patient's information depending on the user, though proxies can be linked to several patients (their children). Physicians can customize whether messages should go directly to them (rather than being triaged first), to whom their message should go (to the proxy only or to both proxy and child), and whether or not an electronic reply to their message is allowed.

CHAPTER 3
BACKGROUND

Chronic illness is a pervasive problem that affects multiple aspects of the adolescent's lived experience. To better ground my research within chronic care, I first provide background on the problem space by bringing in perspectives from health and social sciences related to illness narratives and management. I describe current barriers that prevent pediatric patients from participating in their care, and review related theoretical work to examine the applicability of existing HCI research to this group. In the last half of the chapter I introduce patient-generated health data, a central topic in my research, and review work on patient-reported outcomes and observations of daily living.

3.1 Narratives in Health Care

3.1.1 Illness Narratives

In order to properly introduce the concept of narratives in the context of my research, I subscribe to the biopsychosocial model of illness. In this view, illness is socially constructed [63]. For example, while the biological illness resides in the patient's mind and body, the ways in which patients and family members experience illness are inseparably connected. Arthur Kleinman, a prominent physician turned anthropologist, attributes a broader definition to illness than it is conceived in a biomedical model (e.g., disease) [64]. In his definition, illness refers to *how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability*.

Following from Kleinman's definition of illness, medical anthropologists and sociologists argue that patients construct narratives to give meaning to their illness. More precisely, illness narrative is a form of meaning making through giving words and meaning to one's

lived experience [64, 65]. An *illness narrative* has thus been conceived of as a patient's autobiographical (own) as well as biographical (family member's) account of her illness and the effects of illness on her life. As Kleinman puts it,

> "*Each patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings that make sense only in the context of a particular life*." [64]

Allowing patients to lead their illness narrative has several advantages. When told by patients, narratives have important therapeutic value—giving words and meaning to one's experience itself is a healing process [66]. Narratives also allow clinical practitioners to provide effective care to patients by giving them a chance to look into the patient's illness problems (beyond treating the disease), and relieve them of certain distresses that come with the experience of living with the illness. For example, upon listening to a patient complaining about an inflamed joint, clinicians can provide behavioral and dietary guidance on how to reduce the inflammation. But this guidance must be tailored to the patient's and family's life style, family dynamics, socioeconomic status and context of living. To establish such high quality of care based on illness narratives requires that doctors develop significant capacity for empathic witnessing, as Kleinman calls it, which is the ability to elicit, interpret and translate the patient's illness narrative [64].

3.1.2 Narrative Medicine

The concept of illness narratives has been widely accepted and applied to training in medical schools, through the field of narrative medicine. Rita Charon, a physician and literary scholar, introduced the concept of 'narrative medicine' as a theoretical paradigm, to encourage practitioners to "recognize, absorb, interpret, be moved by, and act on patients' illness narratives" [67]. In narrative medicine, medical students are taught to communicate with patients empathically by first understanding the various meanings patients give their

illnesses—instead of trying to solve a biological problem [67]. Empathic witnessing can provide effective means to fill the gap between patients and doctors in clinical encounters, and lead to better health outcomes. For example, a study investigating the effects of physician empathy on 891 diabetic patients reported that patients who had physicians with high empathy scores maintained better control of their hemoglobin A1c levels than those who had physicians with low empathy scores [68].

Drawing heavily on literature theory, Charon postulates that five narrative features can lead to higher empathic engagement between patients and doctors. I describe each of these narrative features in Table 3.1.

Table 3.1: Five narrative features of medicine. Adapted from Charon et al. [67]

Narrative feature	**Description**
Temporality	Being aware of the patients' time and taking time to listen, recognize and care.
Singularity	Recognizing patients experience as unique instead of recurring, replicable experiences across human bodies.
Causality	Gathering and piecing together details of events related to the patient's illness to determine its cause.
Intersubjectivity	Listening to and eliciting patients' first person stories to support personal exploration and discovery of what's meaningful to them.
Ethicality	Fitting language to the thoughts and perceptions and sensations within the teller so as to let the listener "in on it".

These narrative features—*temporality*, *singularity*, *causality*, *intersubjectivity*, and *ethicality*—are grounded in the context of clinical practice, and thus provide guidance to clinicians by highlighting areas that need their attention. However, clinicians face the burden and expectation to recognize, absorb, interpret and act on illness narratives told by patients and their family members.

In many ways, clinicians face significant barriers to attend to Charon's narrative features. Most notably, the feature of *temporality* is often challenged by efforts to optimize patient flow and throughput, allowing them to only spend approximately 13-24 minutes

with their patients [69]. When they are not seeing patients, clinicians use another significant chunk of their time on medical documentation (i.e., EHRs), spending on average 16 minutes per patient visit [70].

The feature of *singularity*, which refers to recognizing individual patient experiences as uniquely different from other patients with the same diagnosis, is perhaps the most difficult to exercise in practice. Clinicians are too often exposed to, and receive training through medical knowledge derived from population or cohort based studies of human health. To comply with value-based programs and their respective reimbursement billing codes, hospitals systematically collect standardized measures of patients' physical and mental health status, such as Quality of Life (QoL) and Patient-Reported Outcomes (PROs) [71, 72].

While physicians can exercise more control over features of *causality*, *intersubjectivity* and *ethicality*, they lack detailed, context-specific guidance on how to prioritize these features in patient-doctor encounters.

The concept of narrative medicine places the onus of empathic engagement on clinicians. While there are opportunities to prepare patients to proactively share their illness narratives and become engaged participants in their care, adolescent patients (in particular) face many barriers in doing so. I describe some of these barriers in the following section.

3.2 Barriers to Adolescents' Engagement in Care

3.2.1 Participation in Care

There is now a growing consensus in the medical community that argues for the transformation of the "patient"—from a dependent recipient of care, to an activated participant [73, 74, 75, 76] who is a "whole person" with physical, psychological, social and emotional needs [77]. Adolescents' activation—and what it means for them to be whole—are complicated prospects. Their physical and psychosocial development vary among adolescents. Yet, in the pediatric setting, clinical caregivers have limited means to assess the adolescents' level of psychosocial maturity. There is no clear clinical boundary that sets apart

adolescence from adulthood since the patient's age does not reliably mark the progression of their transition to adulthood [78, 79].

Often, pediatric practice does not even differentiate between childhood and adolescence [80] and the parent–clinician relationship is emphasized. Kientz found that even this relationship is often accompanied by tensions and inequalities [81]. An unintended consequence of these dynamics is that the patient's role as a 'child' during care is perpetuated, while the parents' role as proxy is reinforced, contributing to the difficulties that adolescents face in assuming growing responsibility for their own health.

While there are ongoing efforts in the medical community to ease the participation of pediatric patients through transition-of-care programs [82, 83], prior research in medical practice has focused on broad systemic changes needed in health care delivery programs and resource management such as staff training and patient education [83] rather than on the role technology can play in supporting patients' participation in their care—an important gap that motivates my work.

3.2.2 Adolescent Privacy and Access to Health Data

Protection of adolescents' confidentiality in relation to their proxy has been a recent topic of interest in Health Informatics, with important medical, social and legal implications [84]. Medical communities are aware of the implications of making electronic medical records accessible to minor patients: special requirements and challenges have been outlined, with emphasis on issues concerning the patient's privacy and their access to sensitive health information [84, 85]. Concerns over lack of perceived confidentiality may deter adolescents from seeking medical care, including consultations with their doctors [86, 87]. Indeed, patients' development of self-care skills and achievement of autonomy is critical for long-term outcomes. The Society for Adolescent Health and Medicine expressed this viewpoint, stating that "confidentiality protection is an essential component of health care for adolescents because it is consistent with the development of maturity and autonomy

and without it adolescents will forego care [87].”In theory, a PHR could alleviate some of these concerns by providing different viewing experiences for adolescent patients and adult caregivers. Yet, efforts toward designing for adolescents are still in their early phases [88, 89].

Tackling issues of privacy and the delicate communication needs of adolescents are important gaps that need to be addressed through human-centered approaches to design. I consider these issues in designing a personal mobile health system to elicit experiential data from both adolescents and their parental caregivers.

3.3 Theories of Chronic Illness Management

Behavior change theories feature prominently in self-management interventions aimed at modifying behavioral determinants of health over time. As such, they are well-suited to applications that promote self-management of behaviors to focus on illness needs, such as those related to diet [90], physical activities [91], and medication adherence [92]. While behavioral factors alone were neither the cause nor treatment for the illnesses I study, it is reasonable to expect that acclimating to new responsibilities, such as recognizing problematic symptoms and administering one's own medications, has dramatic behavioral implications for adolescents. Below I describe individual behavior change theories as well as peer-based social theories that are related to this dissertation[1]

3.3.1 Individual Behavior Change Theories

Popular models of behavior change include the Transtheoretical Model (TTM), which characterizes an individual's readiness to change behaviors, defining the stages through which she can progress in modifying them and processes governing transitions between those stages [94]. While TTM can be useful in situations in which it is clear how to allocate

[1]While community based theories and ecological systems theories [93] also provide rich perspectives on chronic illness management, discussion of these theories is out of scope for this dissertation.

someone to a stage, adolescents with complex chronic illnesses and their readiness to engage in behavior change is expected to be sporadic as they encounter unexpected illness experiences that are less controllable.

On the other hand, the Health Belief Model (HBM) posits that people's beliefs (with respect to the severity of their illness, perceived barriers and benefits of self-management) affect the way they behave [95]. Yun and Arriaga [28] advocate for the use of HBM in the design of interventions to increase awareness of symptoms and knowledge of disease process in adolescents, as it allows us to account for their perceptions rather than assuming a certain cognitive stage.

3.3.2 Peer-based Social Theories

Both TTM and HBM models have been used extensively in HCI research, but give undivided attention to the individual rather than taking into account social influences such as peers and schooling that are unique to adolescent development. As such, peer-based social cognitive models of behavior such as social validation [96] and social comparison theory [97] have informed the design of persuasive systems for adolescents' health-related activities [98]. These models emphasize the tendency to assess one's abilities in relation to a social group to drive behavior change. For example, Chick Clique [99] made step counts of small groups of adolescent girls visible to each other to motivate physical activity. Other systems such as StepStream [100], AHPC [101] and iFitQuest [102] saw the benefits of school-based deployments as they can leverage existing social structures–rituals, space and time–to promote and sustain physical fitness. While peer-based social models may work for adolescents who are similar to a target social group, teens with complex chronic illnesses are unlike peers in their existing social structures. They are bound to frequent hospital visits and must balance large academic workloads with care activities. Their social and emotional well-being is challenged due to ongoing stress associated with diagnosis, treatment, social stigma and uncertain expectations about their future health status [103].

3.4 Patient-Generated Health Data

Patient-Generated Health Data (PGHD) are "health-related data—including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information—created, recorded, gathered, or inferred by or from patients or their designees (i.e., care partners or those who assist them) to help address a health concern" [104]. In its definition, PGHD are described as being distinct from data generated in clinical settings and through encounters with providers in two ways: (1) patients, not providers, are primarily responsible for capturing or recording these data; (2) patients direct the sharing or distributing of these data to health care providers and other stakeholders.

Thanks to advances in multi-modal sensing and mobile and ubiquitous computing, research in PGHD has gained momentum over the recent years, giving rise to new tools that capture patients' health-related data in everyday (non-clinical) contexts [104]. In 2011, The Office of the National Coordinator for Health IT (ONC) has identified PGHD as an important issue for advancing patient engagement and outlined an agenda for providers, researchers, and policy makers to expand knowledge about the value of PGHD and approaches to implementing it [104]. Despite these advances, several barriers spanning data capture, transfer, and review prevent seamless integration of PGHD into clinical communication and practice. In a paper summarizing lessons from Project HealthDesign [2], Brennan and Casper highlighted an important problem that patients faced when managing their health outside of the clinical context:

"*Through Project HealthDesign, we learned that to patients, health is more than clinical signs and symptoms, prescribed diets and drugs, doctors and devices. More importantly, the things that patients attended to, the language they attached to those phenomena and the ways in which becoming aware of this information stimulated health action, and the language used to describe those things was often substantially different from that used by*

[2]Project HealthDesign is a national PGHD initiative research program (February 2006 through June 2014) that was funded through the Robert Wood Johnson Foundation [105].

health professionals. Indeed, not only were the traditional terminologies of health inadequate to express the phenomena of interest, but the very structure of the terms and the purpose they served in the individuals' lives were markedly different from the signs and symptoms terminology employed by clinicians to denote meaning in health." — [106]

Noting this mismatch between the information and communication needs of clinicians and patients, the authors identified two types of PGHD that inform health care: *clinician-defined and patient-generated*, and *patient-defined and patient-generated health data*. In their definition, *clinician-defined PGHD* are assessments that professionals find important, but that must be gathered by the person experiencing daily life to contribute to those assessments. An example of *clinician-defined PGHD* includes Patient-Reported Outcomes (PROs), which are gradually being integrated into clinical workflows as standardized instruments to measure and compare treatment outcomes across multiple patients [107]. On the other hand, *patient-defined PGHD* reflect concepts that are uniquely defined and seen as important by the patient, that can occur dynamically and provide personal indicators of health status. The authors introduce Observations of Daily Living (ODLs) [106] to provide an organizing framework—which is central to my research—that describes PGHD reflecting the patient's perspective.

In the following sections, I describe Patient-Reported Outcomes (PROs) as a type of clinician-defined PGHD, and Observations of Daily Living (ODLs) as a type of patient-defined PGHD.

3.4.1 Patient-Reported Outcomes

PROs are defined as "any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [108]. Such interpretation-free nature of PROs allows it to offer valuable and unique perspectives on the effectiveness of treatment. For instance, physiological (e.g., lab results), physician- (e.g., global impression) or caregiver-reported assessments may not

reflect how a patient functions or feels, whereas PROs may be more reliable for understanding some treatment effects that are only known to the patient. Example data types that can only be obtained from the patient include: symptoms that are not obvious to observers (e.g., pain, fatigue, nausea, etc.), psychological symptoms (e.g., depression, anxiety), symptoms in absence of an observer (e.g., sleep, etc.), frequency and severity of symptoms, impact of a condition on the patient's daily life, and overall patient's quality of life and satisfaction with care [5].

PROs are most helpful in determining the health-related quality of life (HRQOL) [109] of cancer patients, whom are likely to experience challenges living with the illness due to effects of routine treatment cycles. Monitoring the effects of cancer treatment is especially important in the early phases of chemotherapy since successful treatment is contingent on the careful balance between the effectiveness of treatment doses and their toxicity to the patient [13].

When integrated into Personal Health Records (PHR) and patient portals, well-implemented PROs have the potential to empower the patient to take ownership in managing their health through improved collaboration and communication with clinicians [110, 111, 107]. Currently, electronic PRO systems for cancer care are designed to serve two different goals: 1) treatment-centered systems designed for patient monitoring during active cancer treatment, and 2) systems following patients across treatment and survivorship periods [110].

Patients' management of symptoms can be effectively achieved through meaningful communication with their care provider. Through a systematic review, Chen et al. reported strong evidence that routinely collected PROs in the oncology setting improved patient satisfaction, patient-provider communication, monitoring of treatment response and the detection of unrecognized problems [112]. Recent work has demonstrated the feasibility of incorporating patient-reported data into prostate cancer care through dashboards reviewed collaboratively during consultations [113].

Patient vs. Proxy Reports

Despite the known benefits of integrating PROs into care, existing PRO measures are insufficient when used alone to capture nuances of the adolescent patients' experience. First, due to concerns over children's ability to grasp abstract concepts or articulate self-assessed internal (e.g., mood, pain, etc.) and external (e.g., behavioral) health states, self-reported assessments of minor patients are most likely delegated to a proxy report, or caregiver-reported assessments. While parents as caregivers can provide a useful perspective on the child's health status, proxy-reports require them to make inferences about the child's subjective experience—a measure that is hardly consistent with the patient's actual felt experience [108]. The FDA guidance on PRO instruments thus advises caregiver assessments to be observational measures rather than proxy (see Appendix B.3 for a breakdown of types of caregiver-reported outcomes).

Yet, in pediatric care, even for patients who are on the cusp of transitioning from adolescence to adulthood, caregiver-reported assessments are common and more often heard in the clinic—which is alarming. Prior research in care relationships in the pediatric setting show that young patients depend on proxy reporting of symptoms and related experiences by parental caregivers, which often differ from the patient's assessments of symptom severity [114], behavior [115], and quality of life [116, 117]. Considering the link between higher levels of disagreement and negative health outcomes [118], and parents' tendency to dominate clinical conversations [1], the disproportionate representation of patient self-reports is concerning. While more studies are being done on this topic, spanning various measures and conditions, they place more emphasis on understanding whether and where there is disagreement between child and parent reports. Very little attention, however, has been given to the challenges associated with establishing appropriate content validity when developing PRO instruments and accommodating patients' communication preferences when implementing the data collection tool.

Second, it is also unclear whether traditional survey protocols employed by these stud-

ies to elicit patient-reported health assessments are designed with proper consideration for the linguistic and cognitive abilities and attention span of young patients. These factors have profound implications for the design of PRO instruments, including, but not limited to, the language used in instructions and questions, frequency of data collection, recall period of the target experience, and length of the questionnaire. For example, many commonly-used child-reported measures have a recall period of 30 days [109]. This could be problematic for young patients who may not have yet developed the cognitive skills necessary for comprehending time frames [119]. Regardless of the patients age, the FDA PRO guidance [108] states: "PRO instruments that call for patients to rely on memory, especially if they must recall over a long period of time are likely to undermine content validity." Based on this guidance, a task force report on good research practices for pediatric PRO instruments has recommended recall periods of 24 hours or less [119].

Third, there is sound reason to examine the methods used to achieve content validity in pediatric PRO instruments. While the FDA encourages researchers to provide documentation of content validity based on patient input, a recent review of pediatric PRO instruments used in support for medical product labeling cautioned that content validity of child- and parent-reported pediatric measures has often been supported by input from parents or clinical experts rather than the children themselves [119]. Yet there is growing evidence that involving children in the content validation process can be more effective than doing so with clinical experts alone. For example, one study concluded that, when establishing content validity, involving adolescent patients as "experiential experts" resulted in greater relevance of the PRO for the target population [120].

Finally, PROs are "static" measures [121, 122, 123]—typically taking the form of 5-point likert scales, which can fail to both capture and represent nuances of complex internal experiences in patients lives [124, 125].

Currently, a limited number of PRO instruments are available to assess various treat-

ment effects for adolescent cancer patients. PROMIS[3] measures are designed to assess six health indicators—mobility, fatigue, pain interference, depressive symptoms, anxiety, and peer relationships [121]. PedsQL[4] measures seven indicators, including pain, nausea, anxiety, worry, cognitive problems, perceived physical appearance, and communication [122]. The National Cancer Institute recently developed PRO-CTCAE[5] to provide clinical researchers an easier way to customize an instrument (supporting selection from 78 symptoms) focused on capturing patient self-reported cancer symptoms [123].

3.4.2 Observations of Daily Living

In Brennan and Casper's work, Observations of Daily Living are treated as a specific type of patient-defined PGHD [106]. ODLs are defined as "concepts uniquely defined and uniquely important to the patient, idiosyncratically emerging and serving as compelling indicators to the person that either all is well or health action must be taken."

In their view, ODLs consist of three distinct characteristics: status indicators that describe how the patient is feeling (e.g., mood, energy level, appetite), behavioral indicators that describe the behavioral context of the health status or what the patient has done in relation to a particular feeling, and exposures that describe the socio-environmental context. The authors note that ODLs arise within the person's life experience, and ODLs could be used as a foundational language for communicating about experiences, and supporting awareness of those experiences coherently across the domains of both the clinic and everyday life.

ODLs remain a key conceptual framework which guide my research. Its definition is well in line with the concept of illness narratives, which value the unique contribution that patients can provide in telling the story of their lived experience. In Chapter 5, I adapt the

[3]Patient-Reported Outcomes Measurement Information System Pediatric Measures (ages 5-17) v.2.0. (`http://www.healthmeasures.net/explore-measurement-systems/promis`)

[4]The Pediatric Quality of Life Inventory Cancer Module Adolescent Report (ages 13-18) v.3.00. (`http://www.pedsql.org/`)

[5]Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events v.1.0. (`https://healthcaredelivery.cancer.gov/pro-ctcae/`)

ODLs framework to inform the creation of design artifacts for use in collaborative design studies. These cards are used to better elicit everyday illness experiences of adolescent patients and their parents. In Chapter 6, I explore the use of these artifacts in a diary study to support illness documentation and communication for shared health management among family members.

CHAPTER 4
UNDERSTANDING PATIENT PARTICIPATION IN COMPLEX CHRONIC CARE

This project largely consisted of two studies (Study 1 and 2) that provided a holistic picture of the design space of adolescent participation in complex chronic care. Specifically, through individual interviews with patients and their parents, Study 1 provides an overview of challenges that adolescents face when navigating the complex care process with their parents. Study 2 is a long-term investigation that looks at attitudes and perspectives of adolescents and parents toward a tethered PHR system. The following research question guided these studies:

RQ: What challenges and opportunities shape the design space of patient engagement in care processes for adolescents and family caregivers?

In the following sections, I describe relevant findings that answer this research question[1]. Both qualitative and quantitative empirical findings of this research project helped me better understand the design space of chronic care for adolescent patients and informed future research questions for subsequent studies.

4.1 Study 1: Care Partners

4.1.1 Introduction

To map the design space for adolescents with complex chronic illness, I conducted semi-structured interviews with multiple stakeholders, including young patients, their family members and various clinical caregivers. In this study, I specifically focused on understanding the challenges that adolescents face in their care processes. I asked the following

[1]This chapter includes excerpts from "Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care," in the proceedings of CHI 2016 [126] and "Adolescent and Caregiver use of a Tethered Personal Health Record System," in the proceedings of AMIA 2016 [127].

question to guide this effort. What barriers do adolescents face in their engagement in patient-doctor encounters, and how can technology help them overcome such barriers?

This study demonstrates the care that went into understanding the nuanced health needs of ill patient families. In particular, I conducted private and simultaneous interviews with adolescents and their parents to ensure their confidentiality, and in order to solicit candid responses regarding their perspectives toward how they are currently participating in care.

Findings from this research contribute:

- Characterization of three primary challenges associated with adolescents' participation in the care of complex chronic illnesses.
- Examination of the applicability of HCI research supporting chronic illness self-management to this group and identification of opportunities to create patient partnerships with family and clinical caregivers.
- Discussion of how technology can support these partnerships by outlining goals for the design of interventions to support teen involvement in their care.

4.1.2 Related Work

Patient-Doctor Communication

In a pediatric cancer care setting, both adolescent patients and family members play an important role in the patient's care management. Effective communication among adolescent patients, their parents and clinicians has proven to increase the quality and overall satisfaction of the care [2, 3]. Unfortunately, adolescents experience barriers to effective communication during clinical encounters: perceived attitude of the doctor, need for privacy, limited vocabulary or the presence of parents can inhibit discussions that could influence shared decision-making and plans of care [128, 77]. Young people often depend on proxy reporting of symptoms and experiences by parents and clinicians [129, 116]. Yet, parents and their children often differ in their assessments of function, behavior, and quality of life

[130], place different importance on symptoms and their severity [103], and have different preferences for how they wish to receive medical information [1].

Self-Management for Chronic Illness

Medical and social science communities alike recognize the importance of self-management of chronic illnesses: fostering one's ability to manage symptoms, navigate treatments and cope with the physical, psychosocial, and lifestyle changes they bring about [131]. Corbin and Strauss, guided by extensive ethnographic research with chronically-ill patients, specified three sets of self-management tasks involved in living with a chronic illness: medical management, role management, and emotional management [132]. Lorig and Holman [133] and Schulman-Green et al. [134] further expanded on these task sets to identify categories of self-management processes for chronic illness, delineating a comprehensive list of associated skills. For example, chronically-ill people will need to learn to focus on their illness needs by monitoring symptoms, taking medications and making day-to-day decisions in response to their experiences, but they will also need to activate or effectively utilize healthcare resources by reporting accurately about the progression of disease, communicating with clinical caregivers and coordinating care services. In addition, they will need to develop coping strategies to deal with various aspects of living with the chronic illness. This study investigates how we can support adolescents in partnering with family and clinical caregivers to perform such tasks.

4.1.3 Method

Study Setting

With IRB approval, I conducted observations and semi-structured interviews with adolescents, parents, and clinicians recruited at Children's Healthcare of Atlanta (CHOA), in two Cancer and Blood Disorders Centers. I recruited patients who were 13–17 years old, through convenience sampling and IRB-mandated clinician approval. This study included

adolescents with complex chronic illness for which frequent hospitalizations are common, routine diagnostic tests are needed to assess status and management, and treatment decisions involve the consideration of complex symptomatic experiences. Recruitment began in October 2014 and concluded when reaching data saturation in May 2015.

Table 4.1: Patient demographics and illnesses. Diagnosis and treatment are mainly categorized under therapy, remission, and metastatic stages.

ID	**Sex**	**Age**	**Disease (stage/treatment)**
T1	F	17	Cancer (remission)
T2	F	13	Cancer (chemotherapy)
T3	M	13	Cancer (metastatic)
T4	F	17	Cancer (chemotherapy)
T5	F	16	Cancer (remission)
T6	F	17	Cancer (stage IV metastatic)
T7	F	15	Cancer (remission)
T8	M	17	Cancer (remission)
T9	M	14	Cancer (remission)
T10	M	17	Cancer (remission)
T11	F	16	Cancer (remission)
T12	M	16	Cancer (unknown)
T13	F	15	Blood disorder (unknown)
T14	F	13	Blood disorder (remission)
T15	F	14	Cancer (stage II)

Recruitment and Interview Procedure

I conducted 38 individual interviews: 15 with patients, 15 with their accompanying parent(s) and eight with clinical caregivers. For nine of the 15 patients, I also observed consultations to note behavioral patterns in the consultation room and contextualize interview responses. Consultations typically involved the reporting of diagnostic tests and an inquiry into patients' symptoms, such as pain levels and experiences with medication. They lasted approximately 15 minutes each, and researchers were present 5-10 minutes before they

Table 4.2: Clinician demographics.

ID	Role	Experience (years)
C1	Physician	2
C2	Nurse Practitioner	5
C3	Primary Nurse	4
C4	Physician	4
C5	Child Life Specialist	5
C6	Team Nurse	5
C7	Physician	3
C8	Physician	16

began (i.e., while patients and parents waited for the physician to arrive).

Interviews with patients and parents were conducted in private rooms or separated areas at CHOA: only the parent(s)—not their children or members of the care staff—were present during parent interviews, while only the adolescent was present during patient interviews. Interviews, conducted by two researchers (one in each room), were audio recorded, and took place after the scheduled consultation. Interviews with clinical caregivers were also audio-recorded and conducted individually. All interviews lasted approximately 30 minutes.

Analysis

I and two researchers created observation notes through regular debriefings following fieldwork. After transcribing all interviews verbatim, we segmented responses by question-answer turn, cross-referencing clusters with observation notes. Together, we conducted affinity clustering with paper copies of the individual turns. We then applied a hybrid approach [135]: after inductive analysis yielding emergent clusters, we reconsidered as a group each cluster in a more deductive fashion. In this way, we together re-evaluated clusters based on our understanding of the domain and prior findings. This resulted in

some refinements to cluster composition and resultant codes. Data analysis occurred in an iterative fashion from March 2015 to August 2015.

4.1.4 Findings

Adolescents and parents faced challenges related to: 1) patients' limited participation in their care, 2) communicating emotionally-sensitive information, and 3) managing physical and emotional responses. These findings allowed me to distill goals for adolescent patients and parental caregivers that can be addressed through design. I present combined data from both the interviews and observations when discussing themes resulting from the analysis. In reporting on findings, I refer to clinical caregivers with the label "C" and parents with the label "P" while adolescents are labeled "T" (e.g., C1, P2, and T2).

Patients' Limited Participation in Their Care

When asked what they would do if they had a question about a health-related experience, nine out of 11 adolescents preferred to ask their parents first, before their doctor. In further interviews with patients, I discovered two reasons why adolescents were hesitant to ask questions. Some patients shared previous experiences listening to doctors' explanations that they could not understand. Others felt as though they will not receive a comprehensive answer from their doctor. These reasons compelled adolescents to defer to their parents paying attention to medical conversations or asking questions in the clinic.

Some patients believed that their doctor perceived them as being unable to understand detailed explanations, and thus do not go into desired details. As T13 put it, "*Sometimes I tell my mom questions to ask them so that I don't have to ask them. [. . .] they don't want to explain everything to me because they think I won't get it. But if my mom asks a question they'll go into full detail. Because my mom has a strong personality so people usually explain everything to her.*" In contrast, T4 told us that she preferred asking her father questions because he spoke to her in ways that were easier to understand. She said, "*Mostly*

I don't pay attention because I can ask my dad. He explains it better. They [doctors] use too many big words and I don't know all of them, so I just wait 'til my dad tells me."

Communicating Emotionally-Sensitive Information

The separate interviews revealed insights into how adolescents and parents handled emotionally-sensitive information. Typically, patients desired a private communication channel with clinical caregivers when they felt the need to discuss sensitive topics, including sexual health and severe symptoms.

Some patients preferred to have a private communication with clinicians, particularly concerning certain private parts of his body. A patient with testicular cancer stated, "*It's a lot easier when they [parents] leave the room. It's something about it's easier for me to talk personally to a stranger than it is to talk to somebody personally that I see everyday. Maybe I can just tell them my story and then never see them again. I guess that's what makes it easier.*"

In other cases, I saw that adolescents and parents needed a private communication channel for instances typically motivated by the desire to protect one another from emotional distress. Patients shielding information typically manifested as hiding symptoms from parents, not wanting to surprise or worry their parent, and not wanting to delay the parent. One patient expressed this concern, saying that he was hesitant to share details of pain or symptom that he is experiencing. He told us, "*I'll talk to my mom about my health, but only to tell her if I have a new pain or something in my leg. Then I'll be like, 'hey it hurts right here', and she'll say 'how does it feel?' like 'from 1–10', 'do you need medicine?' But like if I want to go into detail. I'll just look it up or see how this pain goes. I don't want to worry her with my problems because I know she'll go insane*".

Managing Physical and Emotional Experiences

Uncertainty in the patient's health status and progression of disease led to increased tensions among patients, parents, and clinical caregivers. Specifically, difficulty in understanding and communicating about the patient's subjective experience (e.g., symptoms, pain level, etc.) seemed to amplify these tensions.

For many parents, talking about their child's experiences was the most challenging part of the communication with physicians. A cancer survivor, P4 lamented on her inability to sympathize with her child's painful experience while receiving chemotherapy, stating, "*It's difficult because all chemo is not the same ... I had like bumble bees stinging me from the top of my head all the way to my toes. She doesn't go through that. So it's kind of hard for me to know. I know she's going through something, but I just don't know what it is.*"

As a common reaction to this struggle, most parents had a persistent desire to probe their child's experiences. Yet patients often complained about inquiries into their physical or emotional state. T8, though he appreciated his parents' concern, told me that he grew tired of questions such as 'how are you feeling?' He remarked, "*A lot of times I really don't want to talk to them about how I'm doing. The biggest question I hated being asked is, 'are you okay?' or 'how are you feeling?' I'm feeling fine until you come here asking me all these questions. I mean they want to know and I appreciated it, but if I've got a problem then I'm not afraid to tell anybody.*"

C5, a child life specialist, shared her thoughts on how and why "prompting" adolescents every time with questions about their status was not effective. She said, "*... in terms of sharing how they're feeling about things, that's gonna come in a conversation that's completely unrelated to kids having cancer [...] a lot of times teenagers are so over hearing, 'how are you doing?' or 'how are you coping with everything?' [...] I think the key is not to push it, and it does come out, just in a different way than it does with some of the younger kids who are a little more forthcoming with how they're feeling about things*."

Limited means for understanding and empathizing with the patient's symptomatic expe-

rience often resulted in conflicting views between patients and their parents when communicating the patient's experience to the doctor. I both witnessed and heard several accounts of patients assigning different levels of severity to what might be a symptom. As T5 remarked, "*Sometimes she doesn't really understand, like how I had a fever like a week ago and she was exaggerating about stuff and I was like it wasn't that bad, so sometimes I don't want her to talk because she'll totally make it a bigger deal that it is.*"

In these cases, parents desired a means of discussing their child's care without the child present. In fact, P5 took T5's experience to be more serious and addressed this concern to the doctor during the consultation. "*Now I can't say this is front of her because she gets mad, but she's been complaining a lot about her head being dizzy...anytime I say anything she's like 'Stop complaining, Mom!' but she really does it at home.*"

Interestingly, I observed that these differences motivated patients to perceive electronic health records (EHRs) as a way to resolve disputes or conflicting interpretations over the patient's experience and health status. When asked why access to the patient portal might be useful, T8 commented that, "*That way we don't have to question or argue about anything that has happened. All we have to do is look.*"

Perspectives on the Role of Computing Technology

Both patients and parents were optimistic about the role of computing technology in their care. For patients in our study, the results of diagnostic tests, such as radiology scans of the site of osteosarcoma treatment, or lab results such as the white blood cell count, served to enhance their awareness of the diagnosis. In particular, radiology images served as a powerful way to relate data back to the patient's physical experience. As T10 explained, "*[The scans] make me feel a little bit like I'm in there. I can see the tumor they point out in my body, so I can see what's wrong with me so they don't have to tell me in some weird way.*"

Adolescents often commented on the value of visual information as a compelling medium

for resolving certain aspects of uncertainty in their care. Several saw the utility of visual information in the context of understanding their illness and preparing for treatment or surgery. T13, when explaining to her favorite doctor, commented that, "*she will be like, [this is] what's gonna happen inside my body—but it would be somewhere else. So I can picture it actually happening somewhere else. And sometimes she would draw something out [. . .] to answer questions about it.*"

4.1.5 Discussion

Through semi-structured interviews with adolescent patients, their parents and clinicians, I was able to pursue insights into the current challenges that adolescents faced in participating in their healthcare (such as in doctor-patient encounters) and understand which opportunities exist for technology to support these challenges.

An important lesson that I draw from this study is that adolescents with complex chronic illnesses will likely acquire self-management skills more from parents or others who have navigated the experience, rather than from their peer group. However, while parents can ideally serve as a model for self-management skills, they themselves lack firsthand physical experience of the illness. Moreover, parents often lacked the knowledge and means to understand how to support patients' participation. This means that adolescents' participation in care is inevitable, and their is a need to support a gradual and dynamic process through which patients can learn from their parental caregivers to take ownership of health-management needs. To support this flexible model of shared health management, I argue that **designers of sociotechnical systems should aim to support both adolescents and parents to acclimate to the role of partner in the patient's care**.

The main contribution of this research is the synthesis of insights from these findings, which I use to generate a set of research agendas that the HCI community needs to address when designing for chronically ill adolescent patients and their family members. I applied Schulman-Green et al.'s [134] conceptual organization of self-management skills to help

structure the research goals, which I summarize below.

Recognizing and Managing Body Responses

For patients undergoing long-term treatment cycles, their successful recovery largely depends on the careful balance between the effectiveness of treatment dosage and its toxicity to the patient. Thus, recognizing emotional and physical experiences has significant importance for patients' well-being and quality of life. While adolescents' assessments of their symptoms can differ from their parents', my findings show that patients engage in self-censorship of the symptom severity as they are reporting their experiences to the parents, would independently decide to raise a health concern only when they felt it became alarming, and are less prone to raise health concerns directly to their doctors. One concern is that this degree of separation in doctor-patient communication can result in lower care quality as such care is based on approximations of the patient's health.

For these reasons, I believe future computing systems should **accommodate patient- and parent-reported assessments of symptomatic experiences and reconciliation of these assessments during long-term therapies**. In the context of managing adolescents' symptomatic responses to treatment, patient- and parent-reported data, collected in tandem, may contribute to better-informed decision-making after a diagnosis, based on richer data allowing for patients' input. For instance, doctors can consider regularly collected data; patients and parents can point to specific events of concern and provide clinicians with more context when needed.

How to encourage adolescents to talk about their illness experience remains a challenging computing question. Yet, one important strategy I learned from my conversations with a Child Life Specialist[2] is the need to ask about their holistic experience, not just their illness. To them, this often meant that they needed to lead with a conversation that starts outside

[2]Child Life Specialists are child development experts who work together with doctors, nurses, and other clinical caregivers to assess and meet the emotional, developmental and cultural needs of each child and family.

of the context of the patient's health status. As they better understand the delicate communication needs of these adolescents, it is important that designers involve non-clinician experts such as Child Life Specialists in addition to the typical stakeholders we tend to include (historically, patients, family and clinical caregivers) in the user-centered design process.

Activating Health Resources

Patients will need to learn how to effectively utilize the health management resources available to them. This includes non-clinical experts, clinical caregivers, and electronic forms of health data.

One useful resource that patients can readily access includes online health communities, which provide both informational and emotional support for their care. Users of these communities are often grouped based on specific diagnoses. Yet, some adolescents in our study were not interested in the experiences of older adults even if they share the same condition. This suggests that online social communities supporting the connection of patients to others with experience and knowledge (but who are neither clinicians nor caregivers) **should base these connections not only on condition but on skill-attainment goals**. Doing so could potentially satisfy adolescents' information needs while easing the burden on a family caregiver to serve as the adolescents' informant.

In the exam room, adolescents seemed hesitant to consider themselves an authority on their own experiences and needs. Doctors often did not tailor explanations to the patient's literacy level, and parents would unknowingly dominate the conversation. These instances suggest that patients, parents and doctors could be lacking a general awareness of their own actions or beliefs that may interfere with the adolescent's ability to participate. In patient–doctor encounters, there is a need to **support situational awareness in clinical environments through the inclusion of cues to action to allow multiple-stakeholder engagement**. For example, adolescent patients, parental caregivers or doctors can be noti-

fied during or after the consultation to become more aware of their involvement during the consultation.

I found that medical terminology and adolescents' limited health literacy presented barriers to their ability to effectively communicate with doctors. On ther other hand, these young patients have strong preferences for using abstracted representations of medical information in making sense of their illness experience. This means that personal health records made available to adolescents should **embody techniques to vary the level-of-detail of information and apply appropriate timing, linguistic framing and graphical rendering to these data to make their presentation meaningful**.

4.2 Study 2: MyChart PHR.

4.2.1 Introduction

While Study 1 provided a useful starting point to understand what the adolescents are experiencing as they participate in care, I still wanted to know what participation means in the context of accessing personal health records (PHR) and electronically communicating with clinical providers.

Today, PHRs show promising opportunities to inform patients about their care and support patient-provider communication through secure means, but research examining how adolescents and their parents use PHRs has largely been limited due to federal and state regulations governing pediatric access to these systems. Some states, including Georgia, began offering patient portal enrollment to adolescents ages 12 and up, with proxy access available to their parental caregivers or legal guardians [136].

This research is thus motivated by the timely opportunity to investigate different information and communication needs of adolescents and their parental caregivers regarding their use of MyChart[3], which is a tethered PHR released by the Children's Healthcare of Atlanta (CHOA) in Summer 2014 (Figure 4.1). This study is guided by the following ques-

[3] `https://mychart.choa.org/`

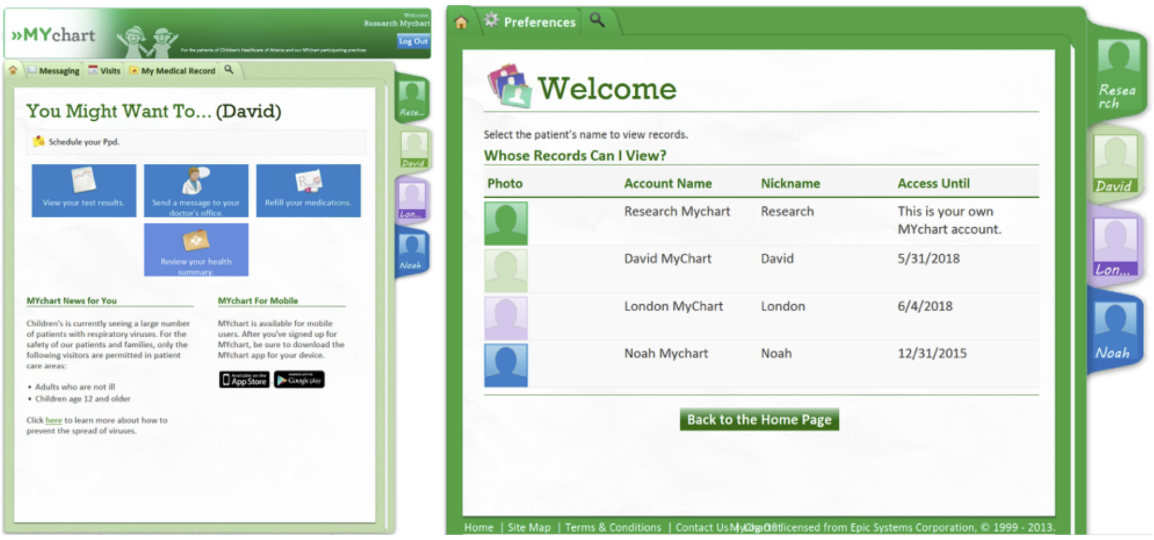

Figure 4.1: MyChart patient portal.

tion. Does the use of a tethered PHR system (when it is available), influence adolescent and parents' participation in care?

Findings from this study contribute knowledge that can help guide the design of health information technology aimed at supporting chronically ill adolescent patients and their parental caregivers. In particular, this study contributes:

- Results of the first study documenting adolescents' and caregivers' actual use and reported experiences with a PHR system.
- First empirical analysis of adolescent patient versus parental caregiver perspectives stemming from their experience with the system.

4.2.2 Related Work

Ongoing efforts to understand adolescents' attitudes toward health IT reveal tensions in information and communication needs of adolescent patients and their parents. For example, a focus group study with adolescents in a pediatric primary care setting found that adolescents had concerns about a lack of confidentiality of their communication, whereas parents were more concerned about "being left out of the loop," or not being informed about signif-

icant health issues [137]. Realizing the importance of privacy in adolescents' care, recent efforts are focused on creating personally controlled health records (PCHRs) that promise accessibility at the level of controllable individual features tailored to each patient's needs [85, 138]. Yet, understanding which communications related to adolescent's health require confidentiality is a particularly complicated problem, making both individual and hybrid models of control challenging to implement, particularly for complex illnesses that require family involvement.

Audit log studies on the actual use of patient portals can provide an empirical complement to self-reported attitudes and reveal gaps in uptake. Such analyses report disproportionate enrollment and use of patient portals by certain demographic populations, particularly including white, adult patients who are healthy and without Medicaid [139]. While patient portals are now available to many, issues of information complexity and usability can hinder their adoption [140, 141, 142]. To our knowledge, these difficulties have only been revealed in studies of adult use of PHRs. One study found socio-demographic disparities in their analyses of portal registrations among pediatric patients: the portal enrollment rate was lower for adolescents (12 years and older) as compared to infants and children (0 to 12) for whom their parents were predominantly involved in the enrollment and activation [136]. Still, no studies of which we are aware investigate adolescents' and caregivers' ongoing experiences accessing a PHR system.

4.2.3 Method

To uncover potential attitudinal and experiential differences between adolescent patients and parental caregivers, I conducted a mixed-methods study comprising: 1) portal usage analysis, 2) small-scale survey, and 3) short interviews. The usage analysis and interviews were conducted to contextualize survey responses.

Recruitment

A total of 46 participants enrolled in this study including assenting patients (n=23) within the ages of 13 to 17 and their consenting parents (n=23). Patients and parents were given separate accounts for logging in.

Portal Usage Analysis

CHOA IT staff verified patient identification and registration and provided audit log data for patient and proxy usage over the study period. MyChart audit data included usage logs collected over a 19-month period ranging from August 2014 to February 2016. I analyzed the data focusing on commonly-used features, when they were accessed, and frequency of access over time.

Survey

Table 4.3: Excerpt of patient survey with selected questions.

Topic	**Category**	**Example Questions**
Context of Use	Closed format	"On which device did you access MyChart most?"
Preferred features	Open format	"What feature was most useful to you? Why?"
Experience viewing content	Likert-style (Agreement)	"Viewing the information in MyChart makes me anxious."
Communicating about health topics	Closed-format (Yes/No)	"I asked someone in my family a question about information in MyChart."
Role of PHR	Likert-style (Agreement)	"MyChart led me to ask questions that I might not have known to ask before."
Reasons to use PHR	Likert-style (Importance)	"When talking about something with my parents."

The survey instrument included a mix of open- and closed-format questions and several five-point Likert-style questions with scales designed to capture attitudes and preferences (Table 4.3). Questions were matched for patients and parents, with minor changes to word-

ing to make sure each question adequately addressed the participant type. I used REDCap[4] to deploy the survey to patients and parents individually, with individual invitations sent after confirming that participants had used MyChart for at least one month.

Table 4.4: Patient and parent survey participant demographics. A total of 10 patients and 15 parents completed the survey. Patient and parent pairs have matching ID numbers. T=Patient, P=Parent.

P ID	**P Sex**	**P Age**	**P Svy**	**T ID**	**T Sex**	**T Age**	**T Svy**	**Diagnosis (stage)**
P3	M	43	Y	T3	M	14	Y	Cancer (metastatic)
P4	F	48	Y	T4	F	15	N	Cancer (chemotherapy)
P5	F	37	Y	T5	F	16	Y	Cancer (metastatic)
P6	F	37	Y	T6	F	17	N	Cancer (metastatic)
P7	F	34	Y	T7	F	16	Y	Cancer (remission)
P8	M	52	Y	T8	M	17	N	Cancer (remission)
P11	F	38	Y	T11	F	16	Y	Cancer (remission)
P12	F	36	Y	T12	M	16	Y	Cancer (unknown)
P13	F	49	Y	T13	F	15	Y	Blood disorder (unknown)
P14	F	47	N	T14	F	13	Y	Blood disorder (unknown)
P15	F	50	Y	T15	F	14	Y	Cancer (stage II)
P17	F	32	Y	T17	M	17	N	Cancer (remission)
P19	F	52	Y	T19	F	15	N	Blood disorder (unknown)
P20	F	56	Y	T20	M	15	Y	Cancer (remission)
P21	M	41	Y	T21	M	14	Y	Blood disorder (unknown)
P23	F	41	Y	T23	F	17	Y	Blood disorder (unknown)

Of the 23 recruited pairs, 12 (52.5%) patients and 15 caregivers (65.2%) responded to the survey. While 12 patients responded to the survey, only ten patients (*mean age*=15.3; *male*=3; *female*=7) and 15 parents (*mean age*=43.3) completed it. Survey responses were excluded if they were incomplete, or if I learned that someone other than the intended participant filled it out.

[4]Research Electronic Data Capture (REDCap) is a HIPAA-compliant web application for building and managing online surveys and databases. `https://www.project-redcap.org/`

Interviews

The study concluded with a phone interview, conducted with adolescent patients and parental caregivers individually, once they completed the survey. Each interview lasted about 15 minutes and focused on confirming participants' responses and eliciting elaboration on open-format responses.

Analysis

I analyzed survey results and portal usage data using descriptive statistics. To explore similarities and differences in Likert-style survey responses between patient and parent groups, I report the difference in mean (mdiff) between the two groups, along with standard deviation (SD) values, for questions yielding the highest and lowest mean difference between the two groups. Below, I include verbal explanations of which group had higher or lower scores to accompany the mdiff value, which is reported as an absolute value. I analyzed participants' interview data through inductive coding to identify relevant themes in an iterative fashion.

4.2.4 Findings

I organized the study findings under three themes: perceived value of PHRs, keeping track of patient's health, and electronic communication and sharing preferences. For each, I discuss patient and parent viewpoints, drawing attention to mean scores yielding the smallest and largest differences. Below, I refer to adolescent patients and parental caregivers as "patients" and "parents", or T and P, respectively.

Perceived Value of PHRs

Analysis of survey responses with the smallest difference in mean showed that patients and parents both perceived MyChart as valuable. Both saw value in using the portal immediately before and after a visit to the doctor's office. Both saw the most value in using it

to navigate the transition from pediatric to adult care. Finally, they agreed strongly about situations when they would not use PHRs. Below I elaborate on some of these scenarios.

After a visit from the doctor's office, patients and parents indicated that they would use MyChart to check that electronic information was correct and review updates to the record. The ability to see results after each visit helped one adolescent patient talk to his doctor. When asked if using MyChart changed the way he talked to the doctor, T12 responded: "yeah, a little. Like one day I was talking [about] how much it [test results/blood level] would drop for my final week of the chemo and he said it would drop a lot and it [did]—it dropped a lot." Both patients and parents agreed to a great extent that MyChart could serve to support the transition from pediatric to adult care over the long term, as well as better support communication with doctors in the short term.

However, not all aspects of MyChart appeared useful to adolescent patients and parents. For example, while both patients (*mean*=4.4; *SD*=1.07) and parents (*mean*=4.6; *SD*=0.6) appreciated the ability to see doctor's instructions or notes in the patient's record, they were hesitant about adding new information or their own notes to the record (patient *mean*=3.5; parent *mean*=3.4; *SD* (both)=1.35). As P7 explained: "*my notes are my part of own notes, but I feel like MyChart... there should just be professional notes—nurses and doctors. There shouldn't be any intertwining, as far as my opinions or my interpretation of that [...] I take those notes for me personally in my journal, my book—not solely relying on MyChart.*"

For some, MyChart was only useful during stages of diagnosis and treatment when patients and their parents were having several encounters with the hospital. Once entering recovery stages and remission, patients saw less value in using MyChart as they did before. T12 expressed this point, "*if something comes up, I would use MyChart. But for now, since I'm in the recovering stage, I don't plan to. Like when I got off chemo, I used it one more time and stopped (using MyChart).*"

Keeping Track of Patient's Health

Analysis of survey responses with the greatest difference in mean showed that patients and parents had somewhat different views about the impact of the PHR on the patient's ability to manage care. Ilearned that both used MyChart to make sense of the patient's illness and treatment process, but they still sought information from external resources to resolve unclear information. Furthermore, adolescents relied on parents to provide explanations of information that was unclear to them. Below, Ielaborate on these findings and provide analysis of portal usage activity and most commonly accessed features.

Perceived ease of use of MyChart for managing care

Overall, parents reported having experienced more difficulty than patients when using MyChart to keep track of their child's health. When asked whether keeping track of the patient's health was difficult, parents showed mixed sentiment (*mean*=3.53; *SD*=1.51; *mdiff*=1.13). On the other hand, patients were more likely to respond that they experienced less difficulty in keeping track of their own health (*mean*=2.4; *SD*=1.51; *mdiff*=1.13).

When compared to parents, adolescents reported a slightly more positive attitude toward the impact of MyChart on their ability to manage their care. After using MyChart, they reported having known more about their health (*mean*=4.1; *mdiff*=0.7) in general and the care their doctor provides (*mean*=3.9; *mdiff*=0.5). They also reported that the information in MyChart led them to ask questions that they might not have known to ask before (*mean*=4.2; *mdiff*=0.6), and had slightly higher expectations that MyChart would lead them to take actions to improve their health (*mean*=3.8; *mdiff*=0.4).

Perceived ability to make sense of illness and treatment

Having access to digital records allowed participants to engage with and understand their health differently. In the interview, P12 reflected on her experiences both prior to and after using MyChart to make sense of her child's health: "they would just give us a paper with the numbers, and the following two weeks we had to go back and they would give us another paper so...I had nothing to compare [the current results] to anything before and I

didn't know where we were actually standing..." Since having access to her child's medical record, P12 shared one of her exciting moments about how MyChart helped her and T12 make sense of the patient's improved health: "When they told us that he was free of cancer, we saw the levels... we saw how [drastic]... that the numbers changed [...] I showed him where it started, during the chemo cycles and when it ended."

Features Accessed

Our analysis of audit logs shows that patients most frequently accessed MyChart features in the following order: Lab Results (25.6%), Messaging (20.4%), Lab Tests (20.3%) and Appointment Review (11.9%). Frequent use of these features support findings of our survey regarding how patients and parents utilized MyChart for clinical encounters.

Most of the study patients regularly accessed MyChart over the 19-month observation period. Participant activation occurred on a rolling basis over the 19-month period and averaged 8.9 months between the time of activation and the last-recorded activity (mid-Feb 2016). Most had periods of inactivity lasting one month or more. Participants logged into MyChart at least once a month (making it an "active month") for an average of 5.9 months. Only three patient participants stopped using MyChart after one to two months of use. While patients were actively using MyChart, the period of active use and number of access attempts varied greatly across patients, as exhibited by wide gap between median and maximum access attempts. For example, T23, the most active user in our studied sample, accessed MyChart every month for the entire observed period and her average monthly access attempts equaled 131.8.

Communication and Sharing Preferences

Analysis of closed-format and Likert-style survey responses revealed insights about how patients and parents prefer to communicate with each other, with clinicians, and other people about their health regarding MyChart. The responses revealed slightly different attitudes and preferences between patients and parents when communicating with clinicians.

Adolescent patients communicated less frequently with clinicians through MyChart than their parents: only one out of 10 patients (10%) reported using MyChart to communicate with clinicians, whereas five out of 15 parents (33.3%) did. Patients' reluctance to communicate directly with clinicians aligned with their preferences for communicating about their health in general: only two out of 10 patients (20%) reported they talked to their clinical caregivers about their health the most—the remaining eight talked to their parents the most and preferred to take questions about their health to parents over doctors. Seven out of 15 parents (46.7%) reported that they talked to a doctor or nurse about their child's health more than they do the child. These findings suggest that parents act as intermediaries between clinicians and their children, even when electronic records are accessible to all.

Adolescent patients and parents also had different viewpoints about their intention to communicate the patient's health status to others, as well as different desires to learn about others like them. When asked if they would like to be able to share their health information with someone else, patients (*mean*=4; *SD*=0.94) agreed slightly more than parents (*mean*=3.6; *SD*=1.18). They also reported slightly more interest than parents in seeing information about other people who have similar health conditions (*mean*=3.9; *SD*=0.99; *mdiff*=0.37).

The patients surveyed indicated having no concerns about what their parents would see in MyChart. When asked if there was information in MyChart that patients would not like their parents to see, all patients reported that they were not concerned. When probed to describe any concerns, most patients reported having none. T23 remarked, "there's nothing in MyChart that I wouldn't share with my mom." The same was true for all parents when they were asked if there was information in MyChart that they would not like their child to see.

4.2.5 Discussion

Many of our findings point to interesting insights about the potential role that health IT can serve in supporting adolescent patients' health management. The following insights informed and shaped my understanding of design decisions that should be considered when supporting family communication for adolescents' care.

PHR was seen as being useful during stages of diagnosis and treatment—shortly before and shortly after clinical encounters. While parents tended to exhibit more difficulty keeping track of their child's health, adolescents expressed more confidence in their ability to manage their care. They sought information in MyChart, and more broadly, the Internet, to clarify information in their records. For patients going through routine treatment, this means that **there is opportunity for technology to proactively support their health needs during active treatment cycles**.

As part of their gradual transition to adulthood, adolescents reconcile who is an authority on their health. Survey results revealed that only one adolescent has reported communicating with the doctor, and parents made more use of MyChart messaging features. Consistent with previous findings [143], most of the patients in our study regarded their parents as their primary information source for health-related information and preferred to take questions about their health to their parents over their doctors. This finding suggests that **while PHR technology supports secure messaging between adolescents and clinical caregivers, parents still assume the burden of communicating about the adolescents' health**.

Adolescents indicated having no concerns about what their parents would see in MyChart, and had more interest in communicating their health status to others. These findings suggest that adolescent patients in my study population may be open to discuss and share their health status with family members as well as other people. Discovering their interest in talking to other people is especially encouraging for my work because it has implications for connecting adolescents to supportive care services. However, **maintaining adolescent**

patients' confidentiality while also meeting caregivers' needs poses challenge for designers of health IT systems.

Innovations in health IT are predicted to play a critical role in decision-making about treatment choices, care continuity, and improved measurement of outcomes of clinical trials. To make PHR systems valuable to adolescent patients and their parents, system design efforts must take into account the **need to reconcile differing assessments of illness-related measures, and different communication preferences of adolescents and parents**. Many opportunities exist for health IT systems to provide age-appropriate mechanisms for reviewing clinical health data, and reporting on health status, health care experiences, and quality of life.

CHAPTER 5

CHARACTERIZING PATIENT-DEFINED PGHD

While Studies 1 and 2 provided an overview of the design space for adolescent participation in care, Studies 3 and 4 focus on characterizing patient-defined PGHD, and generating the necessary design artifacts that comprise a central piece in the design of a mobile health system[1].

Informed by the Observations of Daily Living (ODLs) [106] conceptual framework, I created a set of illustrations (Visual ODLs) that could represent multiple aspects of the adolescent's illness experience. Through my continuing partnership with care providers at CHOA's Cancer and Blood Disorders Center, I conducted co-design research with chronically ill adolescents, their family caregivers' and clinicians to expand on these initial set of illustrations and better reflect their perspectives in the next iteration of design artifacts. Study 3 is my first attempt at using these illustrations, or Visual ODLs, to understand patient and family care management practices related to symptom communication. Based on patient data that I collected from Study 3, our study team digitally recreated patient illness narratives—expressed as Visual ODLs. In Study 4, we used these visual illness narratives to conduct a formative user interface design study with clinicians to understand how to best incorporate patients' visual illness narratives into clinical care. Insights from these studies address the following research question.

RQ: How can we elicit information about patient experiences to create illness representations that are meaningful to them and their family members?

[1]This chapter includes excerpts from "Visual ODLs: Co-Designing Patient-Generated Observations of Daily Living to Support Data-Driven Conversations in Pediatric Care," in the proceedings of CHI 2018 [50] and "Integrating Patient-Generated Observations of Daily Living into Pediatric Cancer Care: A Formative User Interface Design Study," in the proceedings of ICHI 2018 [144]

5.1 Study 3: Visual ODLs

5.1.1 Introduction

Adolescents with complex chronic illnesses have difficulty understanding and articulating symptoms such as pain and emotional distress. Yet, symptom communication plays a central role in clinical care and illness management.

In this study, I first adapted the ODL framework to create a visual library (Visual ODLs) of 72 sketched illustrations. Visual ODLs describe a visual language of patient experiences, encompassing its vocabulary, grammar, and mechanism of expression that enables the patient's comprehension and communication of captured observations and felt illness experiences. I used Visual ODLs in co-design sessions with 13 patient–parent pairs to elicit a rich set of illness experiences to inform pediatric PGHD technology. By providing a visual language, I leveraged adolescent's familiarity and favorable attitude towards using a visual conversational medium while capitalizing on their recognition (thereby lessening cognitive burden).

This study contributes:

- Design artifacts (i.e. Visual ODLs) that researchers can use to draw out and collaboratively reconstruct illness experiences with family caregivers in co-design sessions
- Empirical knowledge that adolescents depicted symptoms as being interwoven with narratives of personal and social identity—in their storyboarding process, aspects of their identity were inseparably interwoven into their illness narratives.
- Synthesis of patient, parent and clinicians' perspectives and discussion of opportunities for co-designing collaborative symptom-tracking technology to support data-driven clinical communication.

5.1.2 Related Work

Research in medicine consistently shows that simple visual illustrations, such as pictograms, can play a significant role in health communication—improving lay people's attention, comprehension, and recall of patient instructions [145, 146] as well as their ability to evaluate and express felt symptomatic experiences such as pain and nausea [147, 148, 149]. Further research shows that this effect can be maximized for patients with low literacy skills such as adolescent patients, and when the intended audience is involved in validating the content of the illustrations [146]. Informed by this research, my work explored the use of co-design techniques to engage young patients in the process of designing visual representations that are meaningful to them.

5.1.3 Clinician Interviews

I conducted individual semi-structured interviews with 11 clinicians (9 oncologists and 2 nurse practitioners) to understand how to design symptom monitoring technology for chemotherapy treatment in ways that support the pediatric care workflow. Clinical experience ranged from 3 to 27 years (*median*=20).

To elicit as much domain knowledge as possible about symptoms relevant to their practice, I used the Pediatric Memorial Symptom Assessment Scale (pMSAS) [150], a 30-item patient-rated and validated instrument developed for adolescent cancer patients aged 10–18, to elicit clinician expert knowledge and their relevant experiences treating cancer patients. pMSAS measures multidimensional aspects of cancer-related symptoms ranging from physical to psychological and global symptom distress.

Interviews lasted 20–30 minutes and each was audio recorded and transcribed for analysis. Two researchers conducted analysis using inductive coding to iteratively generate themes until no new themes emerged.

5.1.4 Clinician Interview Findings

Patient experiences of interest to clinicians

From the list of 30 symptoms presented in pMSAS, I found that the symptoms most important for decision-making included: physical (lack of appetite, lack of energy, pain, constipation, vomiting, mouth sores, nausea, numbness in hands/feet) and psychological (sadness, worry, difficulty sleeping) symptoms, as well as behaviors (physical activity, nutrition, medication tracking, and sleep duration). When asked about specifics of these symptoms, clinicians told us that it is important to know how symptoms affect the patients' quality of life. I also found that most symptoms are evaluated in a descriptive manner. "*Most of them [symptoms] don't have a scale. I would say pain's really the only one we use a scale consistently on. The rest is just, 'What do you mean you're drowsy? How would you describe that?' [For] numbness of hands and feet, what I would say is, 'How often is that happening? Are you having weakness with it? Can you open a bag of chips? Can you hold your pen?' Those kinds of things.*" –C3

Role of symptom tracking in complex care

When asked about the potential role that symptom tracking could play in complex chronic care, all clinicians agreed that patients' self-reports of symptomatic experience would not necessarily impact major treatment decisions (e.g., chemotherapy dosage), but would help them make decisions for supportive care to alleviate secondary effects of the treatment.

Clinicians are focused on attending to acute signs of treatment outcomes (e.g., blood cell counts) and parents call in when their child is experiencing critical symptoms (e.g., high fever). However, both clinicians and parents can overlook non-critical factors usually occurring between visits that can still have long-term implications for treatment. For example, psychological symptoms are often overlooked, but very important to track because it interferes with the patients' propensity to comply with treatment. C3 commented that

depression is the most significant predictor of non-adherence to treatment regimens and engagement in care. "*Sadness, worry, and difficulty sleeping [. . .] are things that if we don't intervene early can become a problem, and lead to not wanting to take your meds, not showing up for your appointments, those kind of things.*"–C3

Reconciling conflicting perspectives

When we asked how clinicians reconcile when adolescents and parents give discrepant reports for observable symptoms (e.g., vomiting) two clinicians (C1, C7) told us they would opt for the "*worst case*" to avoid misdiagnosis. Still, I found that clinicians were receptive to the idea of collaborative tracking among patients and parents. C10 especially elaborated on what this means for tracking nutrition intake. "*Just as an example, I think that a teen should report lack of appetite. But the parent should help report what they're actually eating because lack of appetite is subjective. But a parent can help provide objective information as an outside source on what somebody's eating [...] More like parents for checking, confirming.*" -C10

However, I found that verbal communication did not satisfy the clinicians' need to understand what happened in-between the visits. C1 noted, "*There's plenty of kids [for whom] we'd like to stick a GoPro on their head and just see what happens for the two weeks in between when we don't see them. They come back and we're like: I would like to be in that house and see what's going on!*"

5.1.5 Co-Design with Patients and Parents

I recruited 13 patients (*M*=8; *F*=5) who were 14–19 years old (*mean*=16.5). Diagnoses included Osteosarcoma (3), Ewing's Sarcoma (2), Rhabdomyosarcoma (2), Sickle Cell Disease (2), and other form of solid tumor (4). Patients were currently undergoing treatment (n=8) or had been treated within the last three months.

To better understand patients' illness experiences while receiving treatment, I con-

ducted semi-structured interviews with all participants using storyboarding with scaffolding that included the use of Visual ODLs. The goal for the co-design sessions was to understand how a digital story-boarding tool with Visual ODLs could be designed to enable tracking of symptoms and everyday illness experiences—to support personal review and communication between the patient and their family members as well as with clinicians.

Visual ODL Library

I took guidance from Brennan and Casper's conceptual organization of ODLs [106] and technology probes [6] to construct a total of 72 pictograms, or sketched illustrations of illness-related experiences, that represent people (4), places (13), activities (22), symptoms (13), mood (7), tools (8), descriptors (5). I completed all sketches and the sketches were appraised for clarity by the co-authors. In this library of sketches, physical symptoms and mood indicate status indicators. Activities indicate behavioral indicators, while people and places indicate exposures.

The set of symptoms was identified from the pMSAS [150] during clinician interviews. I derived activities by expanding on Activities of Daily Living (ADL), self-care, Quality of Life, and life-style related activities. Descriptors indicated certain temporal patterns (e.g., occurring overnight, for several days, etc.) or syntax (e.g., can't do) that describe how the individual status and behavioral indicators manifested. Finally, tools described a set of media technologies (e.g., photo, video, chart, seen in Figure 5.1) that the adolescent could bring into the storyboard, to indicate that they wished to capture or communicate an ODL using the tool.

Co-Design Sessions with Semi-Structured Interviews

After obtaining assent and consent from patient families, I explained the story-boarding study procedure and asked patients to review the full list of Visual ODLs. Interviews were conducted in isolated rooms or open spaces depending on the patient's reason for visit. All

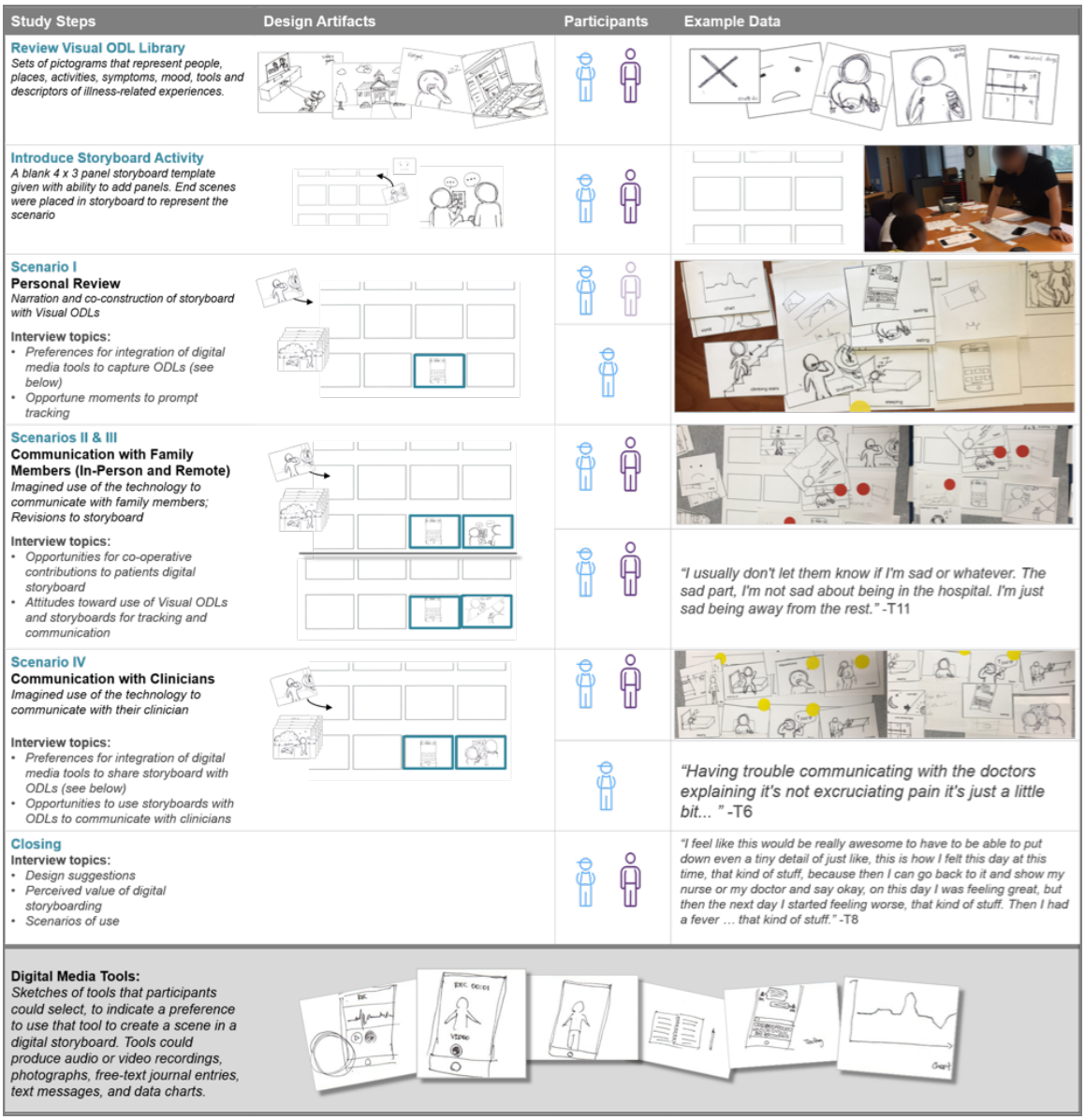

Figure 5.1: Co-Design Process. For each step in the co-design process (top-to-bottom). I describe the step, show relevant design artifacts from Visual ODLs and storyboard and the involved participants, and provide example data generated from that step in the co-design activity. Adolescent patients are shown in blue, parents in purple. Semi-transparency indicates less involvement in an activity.

interviews lasted 30-45 minutes and were audio-recorded.

Using a blank 4 x 3 panel storyboard template as a foundation, we presented four scenarios to draw out illness-related experiences and preferences regarding the imagined use of the technology for four scenarios (Figure 5.1). I chose to scaffold the storytelling process from the end by adding the visual illustrations corresponding to each scenario, in the last panel of the storyboard. End frames were replaced sequentially with each new scenario. Providing this scaffolding for the storytelling process focused on co-designing the beginning and intermittent processes, allowing flexibility to ideate in-between and within Visual ODLs leading up to the resulting scenario of use.

While walking through each scenario, I asked participants to narrate their daily experiences while undergoing treatment. At the end of each scenario, I used a camera to capture the resulting storyboard.

Analysis

All audio recordings were transcribed verbatim. The analysis employed a mixed deductive and inductive coding process [135]. Starting with a top-down approach guided by Brennan and Casper's ODL framework [106], two researchers attached codes to instances of status indicators, behavioral indicators and exposures while noting emergent themes through bottom-up coding. Researchers reached consensus on a list of sub-themes through subsequent debriefings, then iteratively coded the transcripts until no new themes emerged. Emergent themes each corresponded to specific scenarios.

5.1.6 Co-Design Session Findings

Below I organize our findings by scenarios: I, II III, and IV. For each scenario, I highlight relevant excerpts from interviews as well as images of patient-generated storyboards with Visual ODLs.

Scenario I: Personal Review

To introduce patients to ODLs, the first co-design scenario focused on outlining everyday experiences using Visual ODLs. Through this scenario, I established routine activities and learned how symptoms and other aspects of the illness experience unfolded with respect to them.

For all patients undergoing treatment, I found consistency in their day-to-day experience in terms of both structured and unstructured activities that became routines. However, for these patients, symptoms presented themselves unpredictably. The most interesting insights came from patients' reflections on their narrated experiences expressed as Visual ODLs on the storyboard. I found that the Visual ODLs enabled expression of symptoms by 1) enabling the inclusion of surrounding context to better articulate them, and 2) scaffolding how they affected the teen's ability to engage in daily activities. For example, most patients (T2–T13) described their symptoms first in relation to activities and surrounding physical context, drawing attention to how the symptoms affected routine activities (e.g., eating, locomotion and sleep).

I further discovered that patients' understanding and encoding of these associations involved noting the timing, such as onset and duration, frequency, intensity or impediment of specific activities. The visual cues denoting such descriptors aided this process, by providing the grammar for characterizing how the ODLs manifested in routine actions.

In addition, focusing on details about how the status and behavioral indicators interacted helped patients identify patterns of their lived experience. Being able to understand these relationships in better detail was particularly important and motivating for adolescents as it could help them discover behavioral quirks to alleviate unwanted symptoms. As T8 put it, "*I think just to be able to document when I'm not feeling good and how I feel, and then be able to relate from past times and then see what I did to make myself feel better, and to be able to do that again, and then trying to I guess test out things that will make me happy, even if I'm not feeling good*."

(a) Scenario I (b) Scenario II

Figure 5.2: Resultant storyboards of T12 (a) and T13 (b). Both are cancer patients undergoing treatment.

Scenario II & III: Communication with Family Members

The second and third scenarios pursued insights into how family members could work together to contribute their observations of the patient's experience. In reporting the findings, I combine and highlight findings from both co-located (II) and remote communication (III) scenarios.

When I asked what each patient and parent understand best about the patient experience, patients focused on describing personally felt experiences (both physical and emotional) along with how they affected activities that they valued. In contrast, parents filled in 'meta-level' details such as time, location, or frequency of events. However, these details often led to conflicting views about what actually happened. For example, T4 and P4 argued over the child's ability to recognize symptoms.

I found one reason that may contribute to conflicting perspectives. Because parents had significant difficulty understanding how their child is feeling, they relied on subtext, including visual cues such as body language or the child's ability or intention to engage in everyday mundane activities. For instance, P11 told us that he would be able to gauge T11's experiences by reading his body language. While reading body language and behavior helped provide some context, this approach is more applicable to symptoms and activities that are outwardly observable.

Inferring emotions was most challenging for parents. While patients had difficulty expressing emotions in front of their parents, they made use of emotions when story-boarding. In this case, visual representations could provide an alternative means for adolescents (T6, T9) to express their emotions. T6 said, "*it's a lot easier with the pictures because it shows you how mad you are. A picture will explain how mad, visualize how mad you were, how sick you were, how tired, dizzy or something.*" P6 also appreciated the need for Visual ODLs: "*It'd help me understand if he couldn't express to me. [...] Someone not going through it—you don't know how they really feel.*"

Patient families expressed positive attitudes toward the imagined use of digital storyboarding technology as a way to collaboratively contribute unique observations of the patient's illness experience. Parental caregivers, who already had prior experience tracking for the patient, were receptive to this idea. P4 told us that she could offer to help generate the list of routine activities for her daughter T4. "*We could probably make a list, I mean, of her everyday routine, because she's not in school right now, because it's summer ... I don't work, so our focus right now is just her, and getting her through this treatment. So, we could easily map a whole day out.*" On a related note, T13 said that his mother (P13) could help him capture everyday patient experiences through media tools.

Perhaps the most important lesson I took away from scenarios II and III is that both patients and the parent participants saw the value of collaborative construction of storyboards as a point of mediation to resolve conflicting perspectives. T9 posited that tracking ODLs could serve as a point of reference to resolve discrepant recollections of an observed experience, "*but I think that [storyboard technology] would help clear it up. Like with me a lot, my memory's not been the best recently, with all the stuff [chemotherapy] that's going on. So usually it would be me saying something what I believe is correct, and she'll [P9] see it some other way. And if I did record it when it happened, then we could just go back and look at that, and that would help a lot.*"

Scenario IV: Communication with Clinicians

Before starting the story-boarding process, we first asked patients about existing challenges when communicating with their clinician. Several teens stated having difficulty talking to clinicians when they needed to recall illness experiences. This included recalling the timing of the onset of symptoms, recalling behavioral triggers, and discussing severity.

Although patients were accustomed to the use of clinical scales, they had difficulty translating felt experience into numbers. Further analyses revealed that adolescents preferred to express their symptoms in terms of how they affected the ability to engage in everyday activities. When asked how he'd like to communicate his feelings to the clinician, T6 responded: "*It's like how I'm doing something. [...] Sometimes I have to get up and take the shower-head down. That's difficult*."

For less severe symptoms, T10 suggested combining different representations for concurrent or related symptoms. An example of combining facial expressions with other activities helped outline this aspect of such symptom experiences: "*If I was so nauseous that I couldn't eat, or if I like threw up, I could put that on there, but usually it's not that severe... more like, make different faces, I guess, in-stead of neutral, I would be sad*." T7 concurred that, "*I would just tell [the doctor], but my facial expression would show it.*" Overall, patients showed excitement about the potential for digital story-boarding to support their communication of illness experiences with clinicians.

Preferences for Integration of Media Technology

Going from scenarios I to IV, I found that the types of digital media technology adolescents preferred to use to capture and articulate specific ODLs did not change. However, I learned that their choice of technology varied based on the level of expressiveness required to encode how they wanted to capture and communicate the ODLs. Below, I highlight ways in which they preferred to communicate ODLs.

Video was preferred in cases where there was a need to capture the most complex aspect

of the patient's illness experience: how ODLs interact with each other. As mentioned earlier, adolescents (T5, T7–8, T13) wanted to capture the **extent of a physical symptom** by recording how it affects a mundane activity such as eating and dressing. Not only did they see video as a tool for capturing and expressing the illness experience, they also anticipated that videos would be more engaging for clinicians. T5 was optimistic about the potential for video to foster positive patient–clinician interactions, "*Next time I come in, the nurses will be like, 'that was such a cool video [...] of your foot!*"'

Preferences for capturing **emotion**, a highly subjective and complex experience, were mixed. Through storyboarding, patients indicated that **everyday visual depictions of facial expressions** could be a better way relate their mood to clinicians. Among those who responded, many preferred to use sketches from the Visual ODL library, and photos to show their own facial expressions. Yet I found some patients (T3, T7) also needed to use other tools in combination to express different aspects of their mood, such as the use of charts to indicate fluctuating emotions over several days.

Audio or voice recording was seen as a **reminder and journaling tool** to aid the patients' experiencing cognitive difficulties and fatigue. Some patients (T5, T13) chose to record their voice as a way to make journal entries instead of writing and to aid their memory (T1, T6, T13). T13 saw this tool as a way to seek psychological support outside of face-to-face contact: "*If I record they [psychologists] already would know and they could come and talk to me about those things. I don't like to always have people in my face and talking to people because it's boring. Basically I get distracted easily. You can't get distracted from your phone because you're always on it*."

5.1.7 Discussion

Below, I describe several research insights that have implications for personal and family informatics.

Personal Informatics: Activities as a Scaffold for Semi-Automated Tracking

Through the first scenario, I learned that patients undergoing treatment have **highly personal and individualized routines for everyday activities**. The frequent placement of symptoms with activities in the co-design sessions suggests that there are opportunities to leverage the highly-structured, routine nature of adolescents' daily lives in story-boarding technology. While daily entries could be a burden, encoding routines in advance could scaffold the capture of data related to activities and lessen the burden of data collection.

There is a current emphasis on tracking personal health based on a broad interpretation of activities (e.g., physical activity, sleeping) [56]. However, I found that patients were **able to relate better to micro-level activities** such as getting in-and-out of bed, brushing their teeth or reaching for a showerhead. Micro-level activity routines, authored by the user in advance, could reduce the burden of daily logging. These activities can also serve as triggers to help recognize unpredictable symptoms. Establishing daily routines could be used both for manual and semi-automated tracking [57] to elicit data at opportune moments. For instance, given prior knowledge that nausea and fatigue are both experienced as a symptom cluster[2] when the patient brushes their teeth, a system could prioritize the suggestion of those symptoms when the patient is engaged in that activity.

Family Informatics: Collaborative Re-construction of the Patient's Illness Experience

Symptoms are highly individual, often subjective experiences (e.g., nausea and fatigue). Tracking the direct, felt experience is important, and tools should elicit input from both patients and family caregivers [152, 126]. Pina et al. found that families preferred to consider both caregivers and children as trackers, and to distribute the burden of tracking among the family [153].

Family members as well as clinicians found value in the use of collaborative digital

[2]Symptom clusters describe the co-occurrence of a specific set of symptoms for a given illness or effects of treatment [151].

story-boarding to resolve and reconcile different perspectives. Both patients and parents in this study were aware that, when accounting for symptoms, both perspectives, though different, are valuable. Patients understand they have the firsthand experience of their own subjective feelings (e.g., pain, emotion, etc.) while parental caregivers mentioned tracking "objective" details (e.g., time, location, frequency, etc.) of symptoms. In this case, tools that make use of Visual ODLs could **support collaborative work among family members by providing distinct roles** for each stakeholder.

5.2 Study 4: Integrating Visual ODLs in Care.

5.2.1 Introduction

Patient-generated data, such as recorded Observations of Daily Living (ODL) and Patient-Reported Outcomes (PRO) data, are valued sources of information in oncology care. However, prior work largely focuses on capturing clinician-defined, patient-generated health data (PGHD) in oncology care. Emerging research at the intersection of HCI and medical informatics suggests that visual narratives of patients' observations of daily living (ODLs) could better support multi-party review of reported everyday illness experiences and quality of life, potentially improving patient–clinician communication.

In this study, I and a student researcher conducted a formative study with 15 pediatric oncology clinicians[3]. The two phase study informs the design of clinician dashboards for reviewing and interacting with patients' Visual ODL data. In Phase I, we analyzed data from interviews in a pediatric oncology setting, to capture the needs of nurses, nurse practitioners, and oncologists. In Phase II, we constructed two low-fidelity dashboard display prototypes, populated with visual data contributed by adolescent cancer patients, and subsequently interviewed pediatric oncology clinicians who reviewed each dashboard design.

Findings from our study contribute 1) four key design objectives for interactive Visual

[3]In this project, I provided mentorship for a master student, Udaya Lakshmi, who led the design of dashboards, interviews and analysis and manuscript preparation. I contributed equally on the interviews, data analysis and writeup

ODL dashboards in pediatric oncology, and 2) three use cases for clinician dashboards presenting graphical PGHD.

5.2.2 Related Work

Integrating PGHD into Clinical Conversations

Patient-generated health data equip clinicians with information about patient experiences collected outside the clinical setting [104]. Clinician-defined, patient-generated data include Patient- Reported Outcomes (PROs), which are standardized measures for patients to report on their health and quality of life [154]. Though PROs may not reflect specifics about how a patient functions or feels, they provide a reliable method to capture some treatment effects on the patient's quality of life and their satisfaction with their care [107].

While there are concerted efforts by clinicians to adopt PROs in their practice, there are two barriers to integrating them into clinical care [155]. First, clinicians are concerned that patients may not be able to provide complete, relevant, standardized data through self-reports of illness experiences [156]. Additionally, PROs are "static" measures [121]–typically taking the form of multiple-choice questionnaires, which can fail to both capture and represent nuances of complex internal experiences [124].

Advances in personal informatics and the Quantified Self movement allow data collection through passive and active sensing [157, 57]. However, to integrate these data into practice requires that we solve challenges not only in capturing and managing PGHD, but also in displaying it in ways that support clinicians' interpretation of the data.

Engaging Patients Through Visual Communication Displays in Clinical Settings

Recent work in health informatics and HCI has culminated in the design of graphical information displays to support different use cases for patient-centered communication. Exploring the integration of personalized PRO dashboards in follow-up care, Hartzler et al. examined the design of graphical PRO information to effectively represent patient-generated

HRQOL data following prostate cancer care treatment [113]. Since PRO measures are collected using standardized questionnaires [158, 124], graphical presentation techniques are required to structure and present PRO data in graphical displays. Furthermore, even when presentation techniques are designed well to fit the data they depict, the standardized nature of PROs excludes details about everyday activities and situational contexts that are often important in order to "fill in the gaps" [125, 156].

Most studies investigating the role of graphical information in patient-clinician communication focus on communication directed to the patient. For example, in my previous study I have prototyped and pilot-tested a tablet-based interactive radiology report application that supports on-demand retrieval of patient-friendly explanations with anatomical illustrations [159]. AnatOnME demonstrated a projection-based handheld system that allows clinicians to display medical images onto the patient's body [160]. Closer to the study we present in this paper, the BodyDiagrams project demonstrates how patient-generated diagrams can be used to augment text descriptions of patients' pain symptoms to support symptom communication [161]. Extending the use of illustrative techniques to depict patients' symptoms, we explored the role of visual, patient-defined PGHD in communication during pediatric cancer care.

5.2.3 Phase I: Formative Design Interview

Methods

With IRB approval, we conducted 20 interviews over two phases with 15 clinicians at CHOA in two Cancer and Blood Disorders Centers. Clinical experience across participants ranged from 3–35 years (median = 22) (see Table 5.1 for participant details). We interviewed 12 clinicians between March and April 2017 for Phase I. After the patient focused study (S3), we began recruitment for Phase II in September 2017 focusing on solid tumor patients. We concluded when we reached data saturation, in November 2017. The second study includes design feedback from five clinicians who participated in Phase I.

Table 5.1: Clinician participant demography. Y or N indicates participation in Phase I (n=12), Phase II (n=8), or both. NR indicates that years practicing were not reported in the interview(s).

ID	Phase I	Phase II	Role (experience in yrs)	Specialty
C1	Y	Y	Oncologist (35)	Solid tumor
C2	Y	Y	Nurse practitioner (24)	Solid tumor
C3	Y	Y	Oncologist (25)	Solid tumor
C4	N	Y	Oncologist (NR)	Hematology & Solid tumor
C5	Y	Y	Oncologist (11)	Solid tumor & Cancer survivorship
C6	Y	Y	Nurse practitioner (20)	Solid tumor
C7	N	Y	Nurse (NR)	Cancer
C8	N	Y	Oncologist (NR)	Solid tumor
C9	Y	N	Oncologist (25)	Leukemia & lymphoma
C10	Y	N	Oncologist (12)	Leukemia
C11	Y	N	Oncologist (27)	Brain & spinal cord tumor
C12	Y	N	Oncologist (26)	Leukemia & lymphoma
C13	Y	N	Oncologist (7)	Hematology & Cancer survivorship
C14	Y	N	Oncologist (9)	Leukemia & lymphoma
C15	Y	N	Oncologist (3)	Solid tumor

Each interview in Phases I and II was audio-recorded with clinician consent and transcribed verbatim for qualitative analysis. For both studies, we organized clinician quotes to iteratively generate themes until no new themes emerged. For Phase I, we leveraged clinician interview data collected in S3 and performed a secondary data analysis of interviews conducted after a design activity with adolescent patients. We applied themes deductively to arrive at insights pertaining to their review by clinicians. In Phase II, we conducted an inductive thematic analysis of interview transcripts. We noted emergent themes through bottom-up coding, with two researchers evaluating subthemes to reach a consensus over three iterations. Clinicians recruited for Phase II to evaluate prototype dashboards are indicated in the table.

Findings and Key Design Objectives

Clinicians preferred to receive PGHD from patients and parents during treatment. Some preferred to receive data two-to-three times a week (C3, C6, C14) or at a set of times related to treatment stage (C1, C10, C15) and severity of the symptom (C9). Some clinicians also preferred daily-logged patient data (C1, C5, C10, and C11). For example, C5 reasoned that, "*I think ideally you would do it seven days a week because a lot of times kids are getting chemo on a specific day and so you expect their symptoms to change throughout the week.*"

Clinicians have their own process of collecting symptom data from patients called Review of Systems (ROS), which are collected by nurses and nurse practitioners to elicit symptom data at the beginning of each visit. However, ROS data is often an approximation and inadequate method for clinicans to assess the patient's illness experiences. C1 mentions: "*[If] you just pick a number—it doesn't tell you what it is. High distress: ten. [But] there's no scale that we're handed that tells us what this [actually] is [for the patient].*"

Clinicians ask patients and parents to keep diaries for tracking activities occurring as part of routines (for example, food intake) or persistent symptoms like headaches if these are reported by the patient and parent (C2, C3, C6, C9–C11, C13). Specifically, clinicians mentioned headaches as a symptom connected to physiological and psychological effects, relying on in-depth data from patients to characterize and reason about them.

When asked about whether and how parent and patient reports should be emphasized in a PGHD dashboard display, clinicians consistently emphasized their need for both perspectives.

Findings from Phase I in this study contribute four key design objectives (also informed by Study 3) for interactive Visual ODL dashboards in pediatric oncology, including:

- Display relationships between symptoms and activities, with visual representations of modifiers and auxiliary verbs such as "cannot do" an activity
- Allow clinicians to access PGHD in the form of media used to capture symptoms and

other observations (e.g., photos, videos). Contextualize the data captured by indicating when they were captured with respect to ongoing patient-reported observations.

- Demarcate patient and parent contributions of observations of daily living, especially symptom data.

- Enable review of patient-reported symptoms by their frequency, severity and their interference with specific activities in the patient's daily life.

5.2.4 Phase II: Review of Patient-Generated Health Data

Timeline vs. Tabular Dashboard Designs

Following the four key design guidelines, we produced two types of designs that emphasize different aspects of patients' illness experience:

- Timeline view: presents patient-reported Visual ODLs in a chronological manner—from waking up in the morning to sleeping at night. Symptom persistence is indicated by the lines from left to right, across a linear progression of activities performed by a patient on a typical day (Figure 5.3).

- Tabular view: visual ODL data is presented in a tabular view to emphasize the interaction between symptoms and associated daily activities. In this layout, symptoms are placed in the order of frequency and icon placed in the intersection of symptoms and activities denote media data that capture this relationship (Figure 5.4).

Method

We showed clinicians a patient profile persona in the form of a personal, text-based vignette that included the patient's medical history. We produced a composite collection of Visual ODLs from these patients, based on data generated by 11 patients with a diagnosis of solid

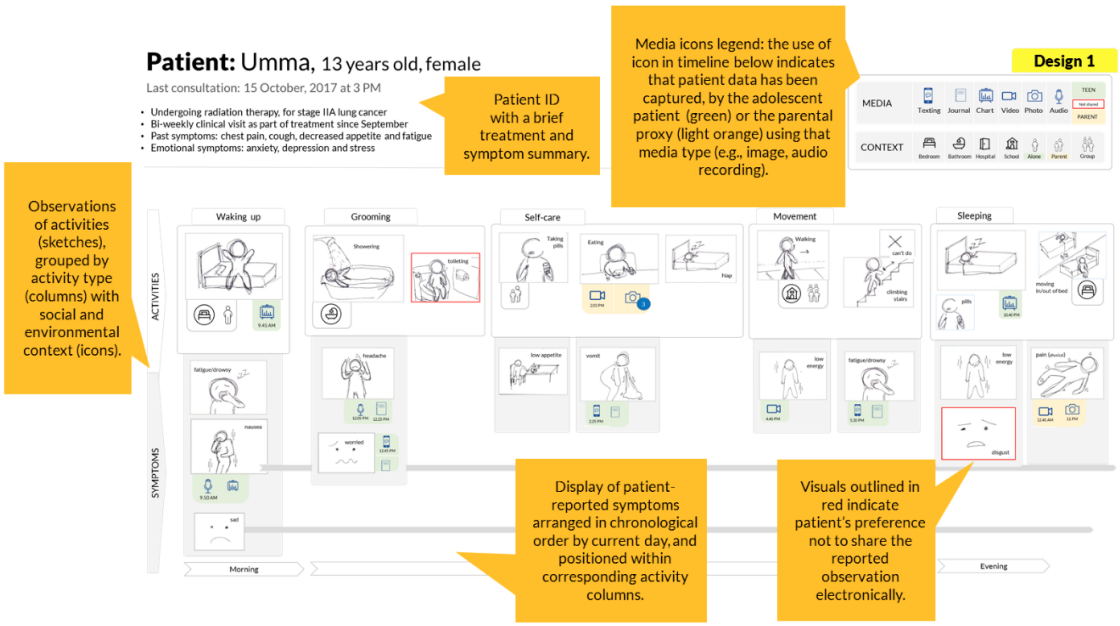

Figure 5.3: Design I: Timeline View of PGHD

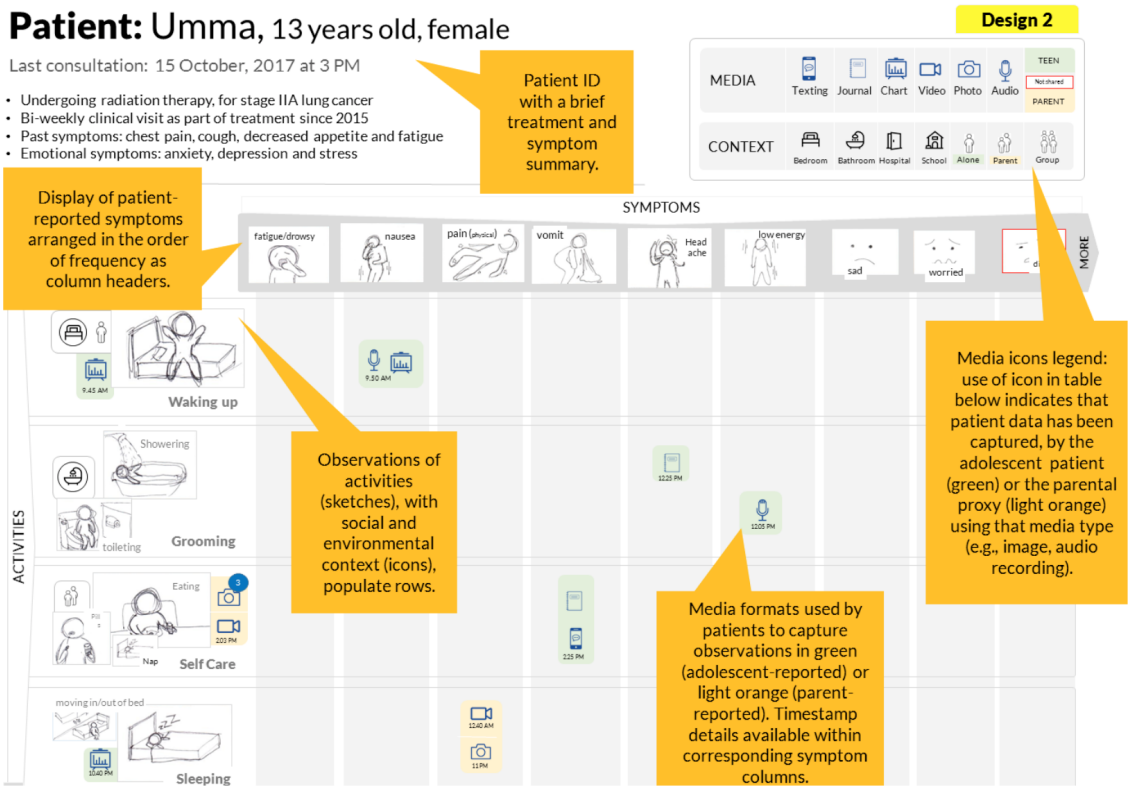

Figure 5.4: Design II: Tabular View of PGHD

tumor, from Study 3, to populate the prototype dashboard design with Visual ODLs created by these patients.

We used a Wizard-of-Oz approach to demonstrate the expected interactions (e.g., tapping) to access media. We used sample patient-generated data shown on mobile devices (e.g., charts, journal entries, photos or audio notes) to help clinicians experience seeing each type of media data indicated on the designed dashboards. Patient and parent contributions of data, are respectively highlighted in green and yellow. Activities and symptoms that patients would not like to share electronically with clinicians are outlined in red to probe discussions about privacy implications of sharing media data.

We conducted design review sessions and semi-structured interviews with eight clinicians. We oriented each review session with a brief, 10-minute introduction to the concept of Visual ODLs, and the two narratives for reading the fictional patient's data, one layout style per design.

Findings

Clinicians were interested in and optimistic about the use of patient-defined PGHDs in their current practice and the presentations of these PGHDs in visual, narrative formats. We organize findings in this section under three use cases for the use of dashboards: reviewing data before the consultation, reviewing data during the consultation, and follow-up remotely between visits. Below, we detail each use case and provide its rationale.

Use Case I: Preparing for the Consultation We asked about the use of the data in clinical communication. Seven of the eight clinicians (all except C5) mentioned specifically that they would review the data before they meet the patient and parent during visit. C5 also alluded to reviewing the summarized data as part of the review of systems.

However, clinicians mentioned that they would use the narratives to update a mental model of the patients' experiences before they met them. Being able to see this history beforehand allows clinicians to prepare a plan for navigating the patient's problems (C3,

C4, C6, C7). Clinicians could organize their conversations with details from the PGHD narratives, as C6 mentions: "*it can certainly expedite a clinic visit because it can make it more problem focused. You know... if you are... you know going in... these are the things we need to drill down and really evaluate today versus, you know, getting this checklist and trying to review it really quickly before you go in the room. And then, you always end up veering off in a different direction.*"

Media shared by the patients could provide evidence for clinicians to probe in discussion. Clinicians were favorably disposed towards images as observational PGHD data, especially for nutrition intake and appetite tracking (C4–C6). However, these media formats need to be summarized as C5 points out: "*Again as long as it's something that I can look at and immediately get the information out that's fine. I guess it's: do I want to look at like 28 meals for the... so it just really depends what the context is.*"

Overall, clinicians referred to using these trends to shortlist which symptoms they would attend to as part of their consultation with the patient during the visit (C2–C4, C8). C8 explains how: "*We as physicians, we typically ask questions in our thought processes that are more symptoms directed. And so we really want to know more: what symptoms are they having, how frequently are they having it, and with the severity of the symptoms.*"

Use Case II: Prompting for Details During the Consultation

Clinicians expected to use the tabular view as an anchor to effectively guide discussion. It could help keep track of talking points without distracting from the main topic (potentially identified from Use Case I). C8 illustrated this point saying, "*You know sometimes when you're talking about symptoms it's not necessarily linear. They start talking about something else or this and that prompts discussion of another symptom. And sometimes when it's not written down or in concrete fashion, it's very hard to mentally keep track, if that makes sense. And so having something concrete like this would help to kind of come back to you know this is what [you logged].*"

The visual means of presenting PGHD appealed to the clinicians. They saw its value

in engaging young patients by offering them the opportunity to navigate the first-person perspective of their illness experience especially through the timeline view. C3 explained: "*You know I think for them to see what they're [logging] they have to pull it up on the screen to, kind of, go through it with you, you know. So, I think with a format like this, that you can visually look at it with the kids, would be helpful.*"

Some clinicians argued for the need to switch flexibly between tabular and timeline views so that they can direct patients to a specific instance. Patients can draw from a specific day to illustrate their self-collected data observations (C2, C4, and C5). C2 says: "*[its] a way to identify, like, one day they're like off the chart for some reason. And then you can go back to that particular day and look at it and then you could also specifically ask the question about that particular day.*"

Use Case III: Follow Up After Consultation

Supportive care for cancer requires coordination among a team of clinicians and clinical staff members, including (but not limited to) physiotherapists, psychologists, nutritionists, family support specialists. Clinicians suggested that the review of these visual narratives can contribute to an understanding of when and how they should involve different members of the care team (C3–C6, C8). C4 commented:"*As the medical oncologist we're sort of like, overseeing their whole treatment plan. And, you know in conjunction with all these other teams. But it's nice to like [...] have a discussion with the psychology providers, psychiatry provider team so that you're all on the same page because these all are really intertwined. So you want to make sure that everyone including the like family and patient are on the same page. So if it just said 'Go do this,' I think there would be a big disconnect for us. It's nice to be able to talk about things... [be in the loop].*"

Nurses could intermittently follow up on how patients are coping with treatment effects by monitoring their daily reported entries of ODLs between visits (C4–C7). One of the nurses, C7, told us that she would prescribe a symptom diary for patients who have reported or exhibited signs of frequent symptom occurrence. While it is common practice for nurses

to follow up with said patients over a phone call a few days after their visit, in this case, C7 expressed a strong desire to see what the patient logged through the timeline view.

Discussion

This study elicits clinician feedback to inform the design of patient–clinician communication technologies that embody the use of patient-defined and patient-generated data in practice. Below, I discuss implications for designing such technology, which also guide my design of a mobile health application.

In cancer care, clinicians often assess the patient's responses to therapy, and evaluate ongoing issues during survivorship, through retrospective, self-reported accounts of the experiences patients have outside of the clinic. From the patient's perspective, these experiences are often situated within their daily activities, spanning multiple facets of living with cancer. Through our study, we found that details requested by clinicians need not relate to patient-identified symptoms alone. For example, the patient's grades in school can reflect indirect indicators of psychological symptoms, social support, and coping. Thus, **narrative layouts that support capture of observations of daily living from many different sources can help to surface concerns that could otherwise go undetected**.

We also found that verbal reports alone may not sufficiently convey what the patient intends to communicate about their symptom-related experience. In these cases, clinicians valued visual narratives along with additional media captured by patients to supplement reports of illness experiences. **Tools to elicit multi-media data from patients should provide guidance for capturing illness experiences** such as video segments by attending to issues of image quality and length of recording.

In the clinic, where their time and attention is the most constrained resource, clinicians can benefit from a summarized "*snapshot*" guiding their attention to problems. This need was reflected in the clinician's unanimous support and preference for the tabular view. Our study highlighted several opportunities and potential scenarios of use for the tabular design.

First, this type of summary could aid clinicians' efforts to mitigate the burden of having to review patient data by distributing the review task among members of the care team. In current practice, each patient encounter starts with the front-line nurse's systematic elicitation of the patient's medical history through the Review of Systems (ROS) symptom checklist, which the oncologists deem as inefficient. Still, they valued the ability to review an overview of the patient's health status between visits and added that the **summary should prioritize surfacing concerning symptoms and the ability to order them by frequency, severity and interference with specific daily activities**.

Second, in the consultation scenario, the tabular view could enable clinician access to comprehensive patient histories of symptom data collected over time. They mentioned using these data to prepare for an upcoming consultation visit, grounding their in-person consultation and investigation of symptom experiences with patient families. **Instead of relying on reactive prompts by clinicians, the tabular view could contextualize the discussion topics they would like to bring up during the consultation visit**. Clinicians remarked on the positive potential to use visual PGHD dashboard designs to engage patients, by prompting explanations of the data collected by them, on a shared in-clinic display.

While all clinicians valued the tabular view, they also mentioned use cases for the timeline view during in-person interactions with patients. Clinicians **could refer to the timeline to note any deviations from the patient's routine**, at the daily level if necessary. Though the timeline view was not their default choice, providing access to a sequential, granular display of a single day was deemed helpful during initial stages of the treatment and for early signs of effects of therapies on the patient's quality of life.

In summary, our findings suggest that both narrative-based layouts support clinician and patient-led communication with patient families by grounding the communication in the patient's observations, collected in situ.

CHAPTER 6

SUPPORTING DESIGN WORK IN EVERYDAY LIFE

My ultimate goal is to design computing technology to engage adolescents and their family members in health management through their collaborative construction of patients' illness narratives in everyday life. It is now possible to tap into adolescents' latent potential to construct rich narratives of their daily experiences—powered by a suit of media technology that are readily accessible through personal mobile devices.

To realize this goal, I employed ecological momentary assessment (EMA) methods that are geared towards achieving high ecological validity by placing the data collection activities in the hands of patients and their parental caregivers, in their natural setting. I call this design work because I wanted to emphasize that my goal is not just to create another data collection tool. It is to co-design mHealth technologies with adolescents based on their design input while providing an experience that will give them some value.

Through my previous work on Visual ODLs (S3), I uncovered potential links between patients' preferences for expressing their illness representations (or ODLs) and their choice of media technology. I also saw opportunities for parental caregivers to contribute their perspectives related to adolescents' illness experiences. To better examine this phenomena, I conducted a take-home diary study[1] in which I ask adolescents and parents to fill out daily to report on their observations of the patient's illness experiences as they occur in the context of everyday life.

The following question guides this research:

RQ: How can we design computing technology to engage adolescents in everyday health management?

[1]This chapter includes excerpts from "Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers," in the proceedings of CHI 2020 [162]

Figure 6.1: Diary probe kit used in our study. Participating patient–parent dyads received two kits to use for data entry, for up to two weeks. Each kit contained two weekly diary booklets, sticker sheets, markers and pencils, a self-addressed, stamped envelope, and an optional camera.

I have addressed this research question by collecting quantitative and qualitative data through the following research instruments: paper diary packet, media probe, and debriefing interviews.

6.1 Study 5: ODL Diary Probe

6.1.1 Introduction

During complex treatment, family members provide the daily setting for patients' illness management—they often take active roles in supporting everyday activities. Indeed, family support is linked to better illness management and health outcomes [163]. On the other

hand, family members also struggle to elicit emotionally-sensitive and difficult illness experiences from those they care for [164, 126, 165].

In this study, I wanted to understand how to best support cancer and lupus patients during a recurring, two-week treatment and recovery period. Designing for this critical period is important yet challenging, as clinicians require intensive monitoring and vigilance between each clinic visit. To do this, I designed and distributed paper diary kits as probes to collect *in-situ* observational data from both the patient and their parents in natural settings. I used daily text messaging prompts to encourage participants' use of various media technologies in conjunction with the diary. I then subsequently interviewed patients and parents to understand their experiences appropriating the probes.

In this section, I describe the design and deployment of a diary probe kit (Fig. 6.1) with 24 participants (representing 12 adolescent–parent dyads). I focused on cancer and lupus patients because they are most likely to experience the benefits of reporting on their daily experiences during treatment and between visits to the doctor's office [166].

This study produced the following contributions:

- A characterization of how patients and parents appropriated diary probes to document and communicate their illness experiences.
- Insights into how technology can support shared illness management for adolescents with chronic conditions: 1) provide scaffolds to recognize physical and emotional experiences in the context of daily activities; 2) help families reconstruct patient experiences; and 3) adapt to individual preferences for capturing, representing and sharing experiences.
- Discussion of the benefits and limitations of using diary probes with adolescent patients and their parents, and the opportunities for HCI research that follow.

6.1.2 Related Work

Family Health Informatics

The HCI community has seen increased awareness of the role of families in shaping health behaviors, as well as concern for the burden of informal caregiving [152]. For example, the personal informatics field within HCI has seen a shift away from "self-tracking" toward family-oriented tracking, as there is a need for design to promote family health and distribute the work of tracking health information [153].

Work in family informatics has explored the benefits of using tracking tools to encourage positive family communication about health, while leveraging existing family routines [167, 168, 169]. However, dynamically changing treatment regimens are common barriers that interfere with family routines and patient involvement in illness management [170], requiring new approaches to design. In addition, when patients' privacy is at stake, sharing sensitive health information among family members can lead to negative feelings of surveillance and violation of trust [164]. Thus, it is important to understand how to design tools that respect family routines while mitigating concerns of patient privacy.

Probes for Everyday Health Management

Over the past two decades, HCI researchers have adapted various versions of Gaver's Cultural Probes [171] to inform the design of new technology applications, or inspire new design opportunities in everyday contexts [172, 6]. Using probes for data collection and design allows participants to acquire and reflect on aspects of daily life that might not otherwise be accessible to researchers. Probes can also facilitate privacy by allowing participant control over which data they want to share with researchers [172].

While probes are often designed as a "packet" to be deployed in an everyday setting, they can also encompass diary studies [173] and longitudinal user studies supported by the increasing ubiquity of mobile devices [172]. Several mobile photo-elicitation studies

successfully adapted the diary study method for self-reporting of everyday health-related experiences, including foods eaten [174, 58], emotions [175], and physical activity tracking [176, 177]. In this study, I aimed to understand the affordances of various media formats, such as photo and video, combined with sketching and journaling, to support patients in capturing and reflecting on their daily illness experiences.

6.1.3 Diary Probe Kit Features

This study sought an understanding of patients' and parents' illness experiences and related daily activities during the treatment period. This is in sharp contrast to studies that focus on the patient alone. Including the parent's perspective underscores that health behaviors and experiences of family members are intertwined [178, 153, 179]. I provided multiple diaries in two kits, for both the child and a parent, to allow families to appropriate them as they chose.

Daily entry template

Each diary booklet contained seven days worth of daily entry templates and asked participants to choose from a given set of stickers or draw to outline their daily activities (e.g., eating, sleeping, etc.) with the associated experiences (e.g., happiness, pain, etc.) on a vertical timeline (Fig. 6.2B).

Each row was designed to contain a single entry—a co-occurring activity and experience sticker pair—along with options for marking auxiliary details such as the time of day (e.g., morning) and immediate social context (e.g., alone, with mom, etc.) and setting (e.g., bedroom) (Fig. 6.2C). For symptoms, checkboxes were used to indicate the severity of the symptom and its interference with an associated activity (using an embedded 5-point Likert-style scale). Additionally, the template included space to capture written notes.

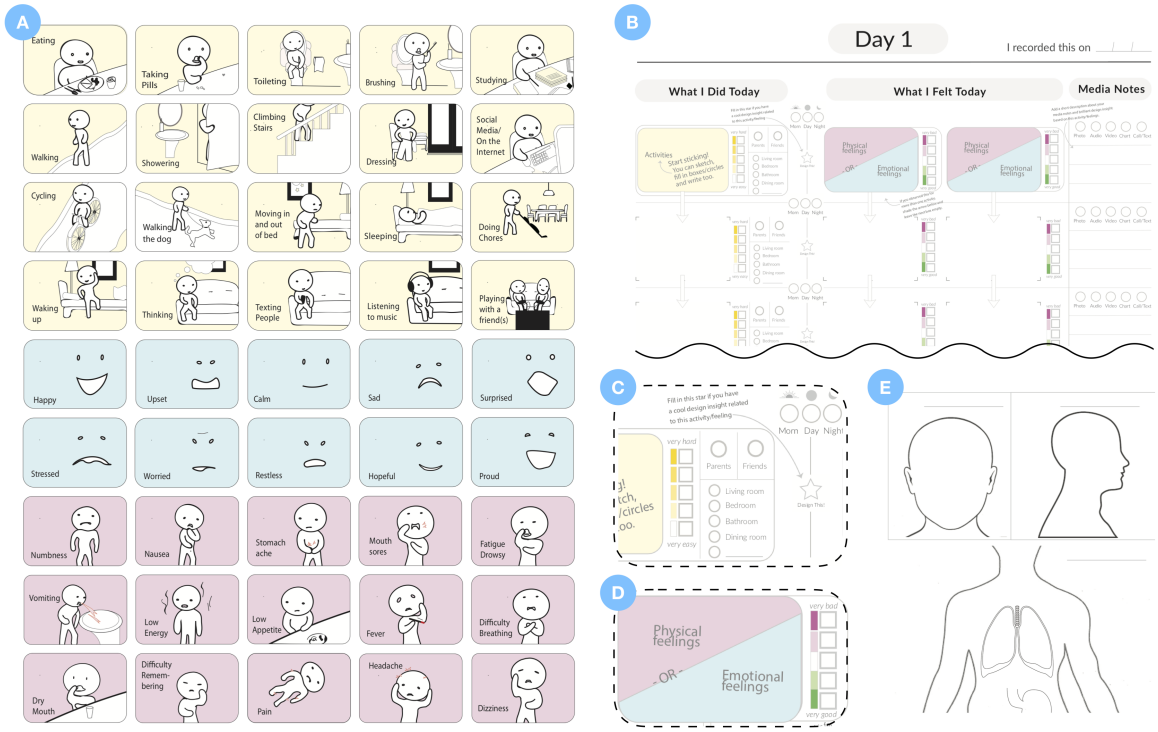

Figure 6.2: Features of the diary booklet. A: Experience sticker sheet contains representative pictograms of common activities (yellow), emotions (blue), and physical symptoms (pink); B: Daily entry template encourages participants to create a story of their day by placing experience stickers in respective columns (marked by matching color) in chronological order; C and D: Multiple response options enable participants to evaluate experiences, time of day, social context and location ; E: Outline of body diagrams are provided to scaffold sketching activities.

Experience stickers

The experience stickers consisted of three sheets containing a mixed sticker set of 16 activities, eight emotional experiences, and 12 physical experiences [50] and two sheets containing a repeating set of the 16 activity stickers (Fig. 6.2A).

Illustrated guidelines

In addition to the guidelines on each diary entry template, I included instructions in the beginning of each booklet, and participants were encouraged to freely elaborate on the template by adding their own annotations (e.g., duration of activities or symptom onset),

drawings, and elaboration. Multiple body diagram outlines allowed participants to sketch their own representation of an experience (i.e., whole body, head, torso, organs, and individual limbs) (Fig. 6.2E).

Caregiver diary

I created a separate parent version of the diary to provide adolescent participants an option to maintain their privacy. Having two diaries allowed me to better understand aspects of the patient's life that parental caregivers attend to. The parents' version of the diary kit included a similar set of instructions, but asked that they record their observations of the child's illness experience.

Media probe

Participants were instructed to use digital media to capture moments of their daily living on their mobile phone or the camera included in the kit. Instead of sending or uploading the recorded data, they were asked to enter a time log at the end of the diary packet whenever they captured data with their mobile phone. I did not require that the participants share the photos with us.

6.1.4 Method

Procedure

I recruited families at a large pediatric healthcare system, in cancer and rheumatology clinics from Aug 2018–Feb 2019. Inclusion criteria for the study included specific patient ages (10–19 years), the ability to speak and read English, a diagnosis of cancer or lupus, an intent to receive routine treatment, and willingness to return to the clinic within 3–4 weeks. After obtaining clinician approval and patient and parental consent, I described the study protocol and scheduled an exit interview with the participants on the day of their next clinic appointment.

Table 6.1: Demographic information of patient and parent participants, sorted by number of diary entries of adolescent participant. #Days and #Entries refer to the total number of days and entries each participant logged in their diary. Some participants completed exit interviews, but did not return their diaries. Patient ID's and specific diagnoses are obscured to preserve the privacy of study participants.

C Age	**C Sex**	**Diagnosis**	**#CDays**	**#CEntries**	**P Age**	**P Sex**	**#PDays**	**#PEntries**
15	F	Lupus	14	188	43	F	-	-
13	F	Cancer	14	171	41	F	13	126
13	M	Cancer	13	166	38	F	12	173
16	F	Cancer	14	152	46	F	14	152
14	F	Lupus	14	141	57	F	14	112
16	F	Lupus	14	129	41	F	14	84
18	F	Lupus	13	106	55	F	14	55
15	M	Cancer	10	81	35	M	14	113
15	F	Cancer	13	81	37	F	7	43
12	M	Lupus	10	46	34	F	6	45
16	F	Cancer	-	-	40	F	-	-
18	M	Lupus	-	-	52	F	-	-

Through convenience sampling guided by our inclusion criteria, weekly screening assisted by nurse practitioners and a clinical research coordinator, and IRB-mandated clinician approval, I initially enrolled a total of 22 patient–parent pairs. Among those who consented, 12 patients and their parents remained in the study for the final analysis ($F = 8$; $M = 4$). Patients were 12–18 years old (*mean* = 15.1).

Text messaging protocol

I sent three daily text messages to patient and parent participants' mobile phones to prompt diary use. The morning and evening reminder text messages included a unique task for the day that asked participants to capture an activity or an emotional or physical feeling using one of the five media probes (i.e., photo, video, voice, drawing, and written note). The tasks were designed such that all permutations were exhausted by Day 14 (the final study day). Participants were still allowed to log freely with their choice of medium outside of

the task. An example task included the following:

> *"After reviewing today's entry, pick one PHYSICAL feeling and use your PHONE to capture how you (your child) felt about that experience with a PHOTO."*

Data collection

The diary data collection period lasted 14 days for each participant. I retrieved the diary kits either by mail or in person before the interview. I was able to retrieve ten patient diaries and nine parent diaries after the exit interview. After the diary data collection period, I conducted semi-structured interviews with each patient–parent dyad. Prior to the interview, I handed the participants their own diaries for reference and asked them to review it privately. Interview topics included: user experience and burden of diary entry, experience responding to different media technology probes, and preferences for sharing and communicating information captured in the diary. Each interview lasted 45 minutes.

Analysis

I and another researcher analyzed 720 minutes of interview data from all 24 participants and responses to the diary booklets from ten patients and nine parents. After transcribing and digitizing all responses to the paper diaries, we included a total of 237 days and 2164 diary entries in the final analysis. We looked for common activities and patterns across participants and differences among child and parent responses. We also qualitatively analyzed participants' sketches of body diagrams in the diary, paying attention to distinct and similar features across patient and parent drawings.

Following an iterative, inductive thematic analysis process [180], we individually reviewed and conducted open coding on all interview and diary entry transcripts to generate emergent themes and subthemes. After several phases of collaborative review and re-evaluation of themes and subthemes, we determined that no new themes emerged from the analysis. In the end, we arrived at six main themes and 26 subthemes. Data analysis

occurred between March and June 2019.

6.1.5 Findings

All 12 patients reported using the diaries during the two-week study period. On average, patients and parents entered data for 12.9 and 13.0 of the 14 days, totaling 129 days of entry for the patient and 108 days of entry for the parent. My analysis of the diary entries (any sticker or added text labels) included a total of 1261 patient and 903 parent daily entries. Qualitative analysis uncovered three primary needs for personal and shared documentation, each detailed below[2].

Scaffolds helped patients recognize and document physical and emotional experiences

When asked about their overall use of the diary to narrate the illness experience, many patients appreciated the stickers, which provided guidance during acclimation to the diary. Patients also told us that they have a difficult time understanding what exactly they were experiencing, but that using the stickers helped them develop more familiarity with bodily sensations. One patient commented that the stickers helped him develop the language needed to recognize and identify his emotional and physical feelings *"It [stickers] really ... put like a word to my emotions. [They] would help [me] come to a conclusion of how I feel."*.

Some patients talked about the importance of focusing on small changes in their symptoms. C15 commented that, as a result of filling out the diary, the stickers helped her describe her feelings for her doctor and family members. *"I learned to pay more attention to how I was feeling, because I didn't used to do that before. Then, if I were to have a flare up, and would have to go to the hospital and explain how I was feeling, I wouldn't know how to do that. So this [diary] helped me explain how I'm feeling, a lot more."*

Many participants told us that the activity stickers in particular helped them recognize

[2]When quoting participants, I code child, parent, and child–parent dyads respectively as C, P and CP.

Figure 6.3: Diary entry excerpt from C13

perceived emotional and physical experiences. One patient told me that thinking about the activities helped him better recall certain problematic symptoms. *"Different activities, like what you are doing before the flare-up. That made me remember that day."* Another patient told me that comfort with activities, such as being able to write for a certain duration, served as an important indication of her physical condition.

Adolescents and family caregivers need support to reconstruct the patient's experiences

My analysis of interview data showed that parents had trouble assessing their child's internal experiences, but did not realize the extent. Parents often relied on external cues and previous observations that would hint at the patient's subjective experience of the illness. However, I found that cues such as posture and facial expression can at times mislead parents. One patient said she could better track her physical feelings and asserted that her parent's observations only reflect impressions, not actual assessments of the true experience. *"I think I can track my feelings better [than my mom] because, from what she sees is*

what she's going to think I'm feeling, but I know what I'm feeling and how I'm feeling." Although patients were aware of this mismatch between their observations and their parents', they did *not* realize how difficult it was for their parents to infer how they were feeling.

By looking at patient and parent entries, I saw that the most frequent activities reported by patients (sleeping, eating, taking pills, waking up,showering, and brushing) resembled those observed and reported by their parents. The dyads also similarly reported on certain emotional experiences (calm, happy, and sad). While patients and parents shared similar activities and mood observations in the diaries, there was a difference in how patients reported their physical feelings. While stomachache, headache, pain, low energy, and nausea were more prominently observed and recorded by parents, patients focused on slightly different categories of illness—such as generalized pain, headache, mouth sores, low energy, and stomachache.

Patient and parent participants included 46 and 26 sketches, respectively. Further analysis of these sketches showed that parents identified the anatomical region of the affected area whereas patients were more likely to add detailed elaborations of sensations onto the diagrams beyond indicating the physical location (Fig. 6.4). For example, C8 utilized different shades of gray to indicate the degree of "tightening" she experienced on her right leg.

Patients learned to pay attention to details of their changing illness experience. Yet many participants agreed that they could reliably document physical activities together. When asked about her experience using the diary, P2 lamented about her inability to understand C2, outside of keeping track of mundane activities. However, it was this ability of the parents to attend to routines that patients valued. C8 suggested that her parent could share the "workload" of documentation, by focusing on activities. *"She [P8] can track me better when I'm doing my activities... that would help split the workload."*

Some families chose to use open diaries. One lupus patient–parent dyad appreciated how the shared diary helped them develop mutual understanding and effective communi-

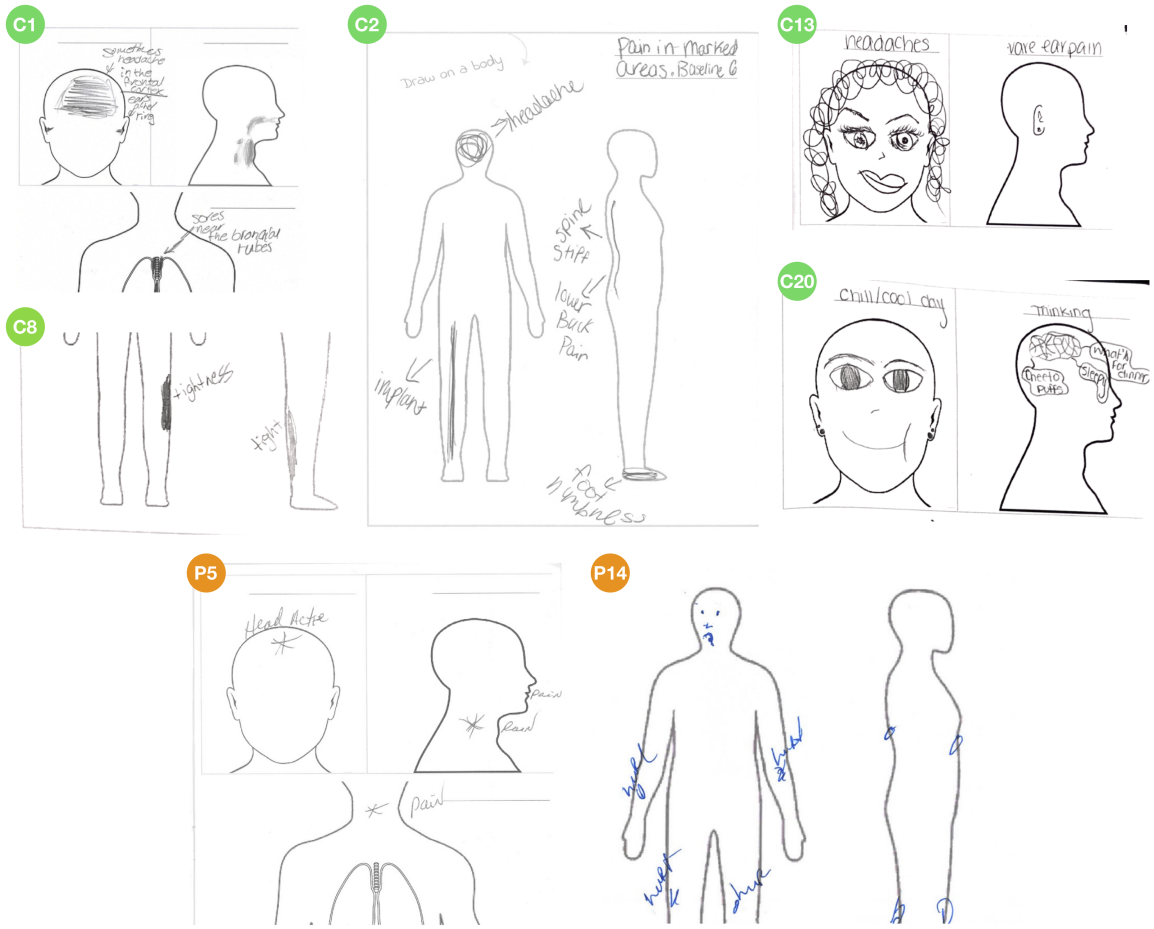

Figure 6.4: Various sketches produced by diary participants.

cation about difficult physical experiences. C13 felt comfortable sharing even her severe illness experiences, which she said she could not do in the usual context of face-to-face communication. P13: *"She'll write it in the diary when it [symptom flare up] happens or when she's feeling it, but she won't tell me until she really needs me, or if I pick the [diary] book up and go through it. I think it helps her. She's able to write it out, loudly, and not have to say it out loudly."* C13: *"[It's] like a silent cry for help. It would just be open."*

Individual preferences drive observation-type, capture and representation of illness experiences

Through the use of diary probes, I discovered that there are individual differences in what illness observations patients want to capture and how they want to represent them. For example, when I asked patients if they used the embedded rating scales (Fig. 6.2C) with symptoms they logged, I received mixed responses. Most participants found the rating scales familiar, but few others who experienced the same symptoms did not think the use of scales applied to their experiences. C2 particularly had a strong reaction to the rating scales. *"I personally hate pain scales, [...] because honestly my pain scales are very different from other people's."* She continued, saying that instead of numeric scales, she describes her pain by asking others to imagine a relatable, but intensified, experience.

Participants took photos of objects (e.g., food) or activities (e.g., doing homework) that they associated with a particular emotion. Some participants suggested that videos would better help them represent their emotional experience. One lupus patient who experimented with videography suggested that videos could help the viewer see the true emotional experience of a person, instead of a desired state of expression. On the other hand, other participants, like C8, told me that using videos to capture their experiences was confusing.

6.1.6 Discussion

In this section I reflect on the insights that were present in the findings and bring in lessons learned from the diary probe study. Many of these discussion points form the basis for design guidelines and goals that point to the design of a mobile health technology for adolescent patients and family caregivers.

Scaffolding collaborative reconstructions of daily life

I learned that the visual design of the diary supported patients in recognizing and reconstructing these experiences. My findings suggest a need to **design effective scaffolds to**

support patients in learning about and representing their illness experiences, such as learning associations between signs of illness and daily activities. In particular, I found that a storyboard format and pictographic representations of activities, emotions, and physical experiences provided the needed scaffolds for patients to compose daily narratives. The media probes helped our participants engage in momentary reflections of their experiences, and allowed them to provide insightful, design-related feedback on the role of different media (audio, video, and photos) to capture their feelings. While the paper diaries contained design elements (e.g., stickers, storyboard template, and body outlines for sketching), these scaffolds did not exist for digital media probes.

Future research should address how to design effective scaffolds to support collaborative reconstruction of the patient's daily experience with digital media technology. As research and design partners, young patients can be actively involved in the process of deciding how to design these scaffolds. In this study, many patients provided feedback on how they wanted to approach the use of various media technologies. For example, some participants used their camera to take pictures of their own face or objects and scenery to represent their mood. Collaborative design processes could build on these preferences to create additional scaffolds and enable personal representations. The challenge will be to do so in an ecologically-valid manner.

From caregiver- to family-centered communication

Caregivers' observational accounts of illness experiences are susceptible to bias when interpreting their child's health status from physical cues such as their facial expressions and posture. In the clinic, there is potential for further influences such as recall bias [119] when reporting experiences. However, the prevalence of caregiver reports can also mean that parents assume a burden to observe and keep track of their child's health between visits [126]. To mitigate this burden, technology should be designed to help patient families share the responsibility of observation and documentation. It will be important to account for dis-

crepancies in observations and to give patients the means to review and contribute amply and flexibly to documentation.

Timing is an important factor in discussing and reflecting on patients' experiences. Grimes' [167] and Lukoff et al.'s [169] findings point to the value of shared co-located routines (e.g., dinner) for facilitating families' collaborative reflection on health data. However, for some patients, sensitive illness experiences were more comfortably shared after some time had passed and outside of the typical context of face-to-face communication. This has implications for designing shared patient and caregiver tools for collaborative review of health information [181, 182]. Rather than implementing a strict open or closed data access policy, my findings point to the need to account for much more nuance. I see important research opportunities to **identify the appropriate timing, types, and level of detail of health-related information to facilitate emotionally-sensitive discussions.** Furthermore, there are important opportunities to explore how to best support informal and formal caregivers and patients to choose data sharing models that maintain autonomy while ensuring patient safety. Families in our study had the flexibility to adopt their own approach to sharing, and they leveraged private, persistently shared, and progressively shared diaries as a result.

From structured to adaptive experience representations

Clinical instruments often focus on standardizing illness representations, forcing patients to translate their experience into a numerical value [121]. Yet, this study shows that valuable information is lost in this translation.

Findings from this study point to the need to **design artifacts that engage with the intersection of quantitative, repetitive, or predefined "tracking", and more flexible, generative approaches** to capturing lived experiences, through probe-based methods. The diary probe not only allowed us to collect data, it demonstrated how an artifact can bridge these two, traditionally separate, approaches. Indeed, "objective" quantified data can be

made personally meaningful through contextualization to communicate personal narrative, identity, and a felt sense of self (instead of creating copies or impressions of reality) [183]. I saw that using both paper diaries and media probes helped patients develop and articulate their personal illness narrative around objective data, in ways that support their autonomy in expression.

How to incorporate flexibility in expression into care processes remains an important question for the HCI community. It will be important to understand how to design and tailor patient-friendly representations for other types of illness data (e.g., nausea, fatigue, etc.) that do not lend themselves to structured scales.

CHAPTER 7
DESIGN GUIDELINES

The overall design of the tablet application was informed by a combination of design insights that emerged from S1–5, including patient family and clinician interviews, and results of the co-design and diary study. In translating these insights into actual designs, I first established solid design guidelines and identified specific design goals from my research that address each guideline. In constructing the seven guidelines, which I elaborate on below, I adhered to the criteria for design guideline development proposed by Amershi et al. [184]. Table 7.1 provides an overview of these guidelines and design goals.

7.1 G1. Elicit the Holistic Illness Experience (Not Just the Disease)

One of the most valuable lessons that I draw from S1, with regards to eliciting adolescents' illness experiences, is the need to elicit an illness narrative that is outside of the context of their health status. While side effects and symptoms provide important information about the patient's experience undergoing treatment, they only comprise a small part of the patient's everyday experience. Treating the patient as a whole person means that we attend to their daily activities, social well-being, proud moments, and thoughts. Such holistic approach to eliciting the patient's experience allows them some flexibility to decide how much information they want to share (or not share) about their health status without feeling pressured to do so.

- **Emphasize documentation of activities as the user's primary task by placing them on the foreground.**

In the co-design and diary studies (S3 and S5), patients often made references to daily activities to articulate their illness experience, and found it to be a good way to structure the

Table 7.1: Summary of Design Guidelines and Specific Design Goals

	Design Guidelines	Specific Design Goals	CO-OP Feature
G1	**Elicit the holistic illness experience (not just the disease)**	•Emphasize documentation of activities as the user's primary task by placing them on the foreground.	•Activity selection
G2	**Provide cognitive support to guide attention**	•Use visual representations to support patient awareness of experiences.	•Experience selection
		•Ensure coverage of various types of experiences for the user to choose from.	•Comprehensive list of icons
		•Provide automated and flexible reminders	•Daily text messaging and notification
G3	**Create personal, relatable experiences**	•Support personalized mobile experiences and respect user preferences	•Profile selection
		•Ensure that the activities and feelings match patients' lived experiences	•Add custom activity
G4	**Support flexible means for expressing subjective experiences**	•Provide flexible ways to associate physical and emotional experiences with specific activities	•Review screen
		•Support expression of both positive and negative experiences.	•Enter details
		•Support flexible expression of illness experiences by providing various digital media technologies.	•Digital canvas
G5	**Attend to privacy considerations**	•Support private mobile experiences for patients and their family caregivers.	•Separate patient and caregiver applications
		•Allow patients and family caregivers to choose their own model for collaborative reconciliation.	•Not available
G6	**Mitigate burden of documentation**	•Remove unnecessary repetition and allow patients to build on established activity routines.	•Not available
		•Support patients and family members to collaborate on parts of the symptom tracking process.	•Activity context (caregiver)
		•Support primary caregiver by allowing other family members to contribute their documentation of observations.	•Switch account
G7	**Attend to adverse events**	•Communicate adverse event to patients and provide relevant resources.	•Alert window

documentation process. To them, activities provide efficient ways to access their memory of associated emotional and physical experiences. For example, structuring questions or tasks with the goal of eliciting whether the patient was able to open a bag of chips or

climb down the stairs can provide more detailed and subtle information (e.g., fine motor skills, or painful knee joint, etc.) about how the specific illness experience has manifested in the patient's quality of life. I also encountered similar comments from clinicians in S4 suggesting that patients tend to recall their symptoms better when asked to describe relevant activities. While clinically validated scales (e.g., PRO-CTCAE) elicit symptomatic experiences in relation to patients' activities of daily living, they do so to a very limited extent by placing symptoms in the foreground—there is a lack of emphasis on identifying specific activities related to the symptomatic experience. In both the diary study and tablet application, I flipped the order such that activities are in the foreground.

7.2 G2: Provide Cognitive Support to Guide Attention

While parents can provide unique perspectives and observations of their child's health status, they lack the 'firsthand' experience that patients have. However, due to the toxic effects of medication, young patients going through complex treatment regimens are expected to experience difficulty attending to and recalling specific instances of their signs of illness. In particular, 'chemo brain', or 'chemo brain fog', is a common cancer-related cognitive impairment that describes thinking and memory problems that can occur during and after cancer treatment. Technology can support patients to overcome these limitations by providing cognitive aids that can help them attend to various aspects of their illness experience and manage their time to document these experiences.

- **Use visual representations to support patient awareness of illness experiences.**

There is an abundance of evidence in medical research that points to the important role that images play in supporting patients' recognition and evaluation of illness experiences such as symptoms [146, 148]. In S3, I created the initial sketches of patient experiences and found them to be a powerful way to elicit adolescents' experience in great detail. In S5, I discovered the potential value that images and accompanying text labels can provide for

adolescents when the images are used to engage them in daily health management. Specifically, the stickers scaffolded patients' process of developing treatment specific health literacy to increase awareness of their ongoing health status. For example, several patients and parent participants in the diary study told me that they stopped using the stickers because they developed the health literacy that is needed to attend to a variety of illness experiences. In the end, some patients were able to document the activities and symptoms from memory without referencing the stickers.

- **Ensure coverage of various types of experiences for the user to choose from.**

'Recognition rather than recall' is a commonly cited usability heuristic [185] that emphasizes the need to reduce users' memory load by making the objects, actions and options visible to them. In order to support patients in recognizing illness experiences that occur in the context of their daily life, I wanted to ensure coverage of various types of experiences for the user to choose from. This was important to understand what activities and feelings to include in a technology designed to elicit the user's everyday illness experience. In S3, I compiled a list of everyday experiences, including activities, physical and emotional feelings, building on established characterizations of activities (such as ADLs and iADLs) and symptom assessment scales (PRO-CTCAE [123], MSAS [150]). While this list provided enough coverage for basic activities and physical symptoms that are expected to occur during treatment, it did not include subtle emotional experiences or other activities that can occur outside of home (e.g., school). To expand on a set of experiences previously identified from research studies, I engaged multiple adolescent patients and parental caregivers in collaborative design studies. These studies allowed me to integrate patients' feedback and preferences into the creation of a set of illustrations, representing 32 activities, 12 emotional-, and 24 physical experiences.

- **Provide automated and flexible reminders.**

Another cognitive aid that technology can provide are reminders. Attention is a scarce resource, and many people, including patients, inevitably need to rely on reminders to better manage important tasks on time. The same is true for adolescent patients who need to balance their time between school work and managing their health. Using the REDCap software's HIPAA-compliant automated text messaging functionality (powered by Twilio software integration), I was able to remind both patients and caregivers to complete their daily entries at three different times periods throughout the day. While patient families appreciated the automated messages, they also provided valuable feedback on how to improve the reminder system. I was told many times that the only time patients can make their entries are before and after school. Moreover, not all families shared the same schedule and suggested that technology should give them an option to flexibly adjust the reminders to accommodate their dynamically shifting schedules and family routines.

7.3 G3: Create Personal, Relatable Experiences

Figure 7.1: CO-OP avatar list for profile creation.

The MyChart PHR study (S2) showed that while personal health information technology is available to adolescents, it did not provide an engaging experience. Creating a patient-facing technology that is also engaging is a challenging task for designers of health information technologies [141]. In the co-design study (S3), however, patient participants

showed high levels of engagement as they were able to exercise control over the presentation of their illness narrative. In essence, I learned that giving adolescents agency to build their own narrative is the first step to making technology personal.

- **Support personalized mobile experiences and respect user preferences.**

One design choice I made was to provide adolescents multiple options to personalize their mobile experience. For example, patients can choose to identify themselves with an avatar from five different skin tones. Their choice of avatar will then determine the skin tone of all images related to emotional and physical experiences. Providing users the option to upload actual photos of themselves can be a great way to create a personal experience. However, the patient population that I studied faced challenges with dramatic changes to their physical appearance, due to the toxic effects of treatment. These effects are very visible, which commonly include hair loss, weight loss or gain, rash, discoloration, and surgical changes to their anatomy. It is important to recognize that adolescence marks a period of heightened sensitivity to self-perception and esteem [186]. Through the use of virtual characters, I wanted to provide users an opportunity to create an identity that they can personally relate to, that does not subject them to negative self-perception.

Through the diary study (S5), I learned there are other ways to support patient users to personalize their mobile experience. As they grew familiar with the initial set of experience stickers, some patients started adding their own personally-relevant activities and experiences in place of the stickers. Informed by this insight, I included an ability to add new custom activities. While co-design studies helped me identify and create illustrations for several categories of activities, patient activities can also be very personal experiences, such as attending a friend's birthday party.

- **Ensure that the activities and feelings match patients' lived experiences.**

While I began with an extensive compilation of activities and physical and emotional experiences, many items in the list did not necessarily relate to everyday experiences that

are typically expected to occur in the adolescent age group (10-19). Managing finances or driving, for example, are activities that are considered too early for young adolescents in junior high school. To ensure that these experiences closely match patients' lived experiences, I engaged adolescents patients, family members, and clinicians in collaborative design studies. I was able to tailor the visual representations and text descriptions of these experiences for adolescents by iteratively refining the illustrations over the course of three studies S3–5 (See Figure 8.2).

7.4 G4: Support Flexible Means For Expressing Illness Experiences

One advantage of using physical design materials (e.g., paper) to engage participants in design research is the ability to give patients full control over how they wish to create or express their experience with the illness.

- **Provide flexible ways to associate physical and emotional experiences with specific activities.**

Both studies S3 and S5 taught me that, for many patients, not all activities are experienced in tandem with physical or emotional feelings. Regardless of when each feeling might occur in relation to daily activities, patients will need time to make sense of, process those feelings, and come to a conclusion about what that feeling was. For example, they might recall certain feelings once the harmful effects of treatment gradually wear off. Sometimes, supporting flexibility is about giving control to the patients. One advantage of using paper based diaries in S5 was that it gave participants control over when and how they wanted to express their feelings. In fact, patients in S5 told me that they appreciated the flexibility in using stickers and paper diaries because they always had the option to go back in time to fill out missing entries. Thus, I designed the app in a way that allows patient and parent users to revisit individual entries to modify or elaborate on their responses.

- **Support expression of both positive and negative experiences.**

Another important lesson that I draw from my prior studies is the need to support both structured and adaptive representations of health data. While clinicians do encourage patients to lead their own illness narratives, they also value structured responses such as likert-type rating scales for efficient medical decision making—to quickly assign degrees of urgency to a large number of patients. I initially adopted structured question and response items from PRO-CTCAE, but found that not all patients find structured response formats relevant to their experience. For example, while validated instruments use negative, unidirectional response options, many patients wanted to express positive experiences too. I modified the response options so that patients can describe the severity and interference of specific activity-symptom relationships through balanced response options (e.g., 2 positive, 1 neutral, and 2 negative options).

- **Support flexible expression of illness experiences by providing various digital media technologies.**

Besides structured scales, I included a digital media canvas to support patients' creative output and flexible expression of their illness experience. Patients in S3 emphasized the importance of both the flexibility of expression through abstract and concrete representations, and through the ability to represent illness experiences in addition to positive life experiences, coping, and self-care tasks that were central to their identity. Allowing patients to mix and use media formats in multiple dimensions of their choice to capture health data could potentially aid the evaluation, recall and articulation of symptom related experiences.

In S5, I explored further how to best support adolescents' articulation of feelings by probing their everyday experience and engaging them in the use of different types of media technology. I found that patients were able to express subjective experiences such as numbness in their feet or tightening of their muscles through drawing sketches. By providing tools that empower adolescents to give form to their feelings and thoughts, we can help them better articulate their health concerns and needs to family and clinical caregivers. S5

shows that digital or paper forms of scaffolds, such as body outlines to provide a frame of reference for sketching, can help patients further express their feelings.

7.5 G5: Attend to Privacy Considerations

Research suggests that adolescents easily forgo health care when they feel their confidentiality is compromised [187]. Preserving the privacy of patients' health data, even within family members, is an important goal that health information technologies should strive to accomplish. I made significant efforts in the design of the user interface and research protocol, and achieved HIPAA-compliance in all aspects of the system architecture to protect patient and caregiver participants' privacy. Yet, my prior studies pointed me to additional insights and considerations needed to provide adolescents the perception of confidentiality in the use of mHealth technologies in their home.

- **Support private mobile experiences for patients and their family caregivers.**

Findings from my early study (S1) point to many delicate tensions between adolescent patients and their parents regarding patient access to health data and communication of sensitive illness experiences. Informed by these findings, and my collaborative work on hospital policies governing adolescent access to electronic health records [181], I learned that the most effective method for preserving adolescents' privacy is to provide individual mobile experiences by default, and allow families to choose their own model for sharing health data in person.

However, focusing on establishing patients' and family caregivers' agreement about the patient experience could be a misleading research goal because parents lack the firsthand experience which are unique to their child (S1). Moreover, S2 showed that adolescents and parents had different expectations about the role of PHRs in their communication and management related to care. From these studies, I learned that designing for adolescent patients also meant that I needed to design for both patients and family caregivers. This is why I

looked to collaborative design studies to better understand the shared health management needs of families, not just the adolescents.

- **Allow patients and family caregivers to choose their own model for collaborative reconciliation.**

While technologies should prioritize providing support for adolescents' privacy, family caregivers also have a strong desire to be kept 'in the loop' to make sure they are providing the best care for their child. In S1, I took note of this tension. While parents lamented about their inability to understand and build empathy for their children, patients often complained about parents who continuously probed their experience.

In S5, I interviewed one patient–parent pair who told me about their experience keeping an open diary. I learned that keeping a shared diary allowed patients to openly communicate their health status (even severe signs of illness) to their caregiver. Yet, I observed that this behavior emerged from a child-parent relationship that can maintain mutual trust for each other: the parent was willing to wait until her child was able to establish a better understanding of her ongoing health status, and the child documented her feelings on the diary. While every child-parent relationship is expected to be different, health technologies can provide guidance on what types of models exist for shared management and collaborative reconciliation of individual assessments of the patients' health status.

7.6 G6: Mitigate Burden of Documentation

- **Remove unnecessary repetition and allow patients to build on established activity routines**.

Creating an illness narrative on a daily basis can be cognitively, physically, and emotionally burdensome for patients and parental caregivers. In S3, I learned that patients go through very few, mostly routine sets of activities during treatment. On the other hand, they told me that their symptoms and side effects can occur unpredictably, at any time of the day.

During the co-design study, one patient suggested a future scenario in which users can save an established activity routine of their choice, and return to the saved routine at a different time to modify, or expand on the routine for easier entry. This way, technology can save patients' time and effort put into entering unnecessarily repetitive information (e.g., activities) and help them redirect their energy towards recognizing and documenting physical and emotional experiences with respect to established activity routines.

- **Support patients and family members to collaborate on parts of the illness tracking process**

As I mention in Chapter 2, A vast number of studies have focused on examining the discordance between patient and caregiver-reported measures of an illness experience, such as symptom severity and quality of life. However, through my previous studies, I learned that this discordance is inevitable because it is impossible for parental caregivers to directly experience how their child feels. I also learned that, because it will be meaningless to compare subjective ratings of the same experience, focusing on understanding ways to distribute the burden of tracking could yield fruitful insights into designing a symptom communication tool for pediatric patient families. For example, findings in both S3 and S5 suggest that caregivers can provide their observations and perspectives regarding the patient's subjective illness experience by documenting peripheral and contextual details.

In my first attempt to address this goal, I designed two different versions of the tablet application in order to provide unique mobile experiences for patients and family caregivers. While both patients and family caregivers are given similar health management tasks, for a given activity, patients are asked to provide the social context (who they were with) and family members are asked to provide meta details such as the time, duration and location in which the activity took place.

- **Support primary caregiver by allowing other family members to contribute their documentation of observations**.

For pediatric patients, the parent who spends the most time at home often assumes the responsibility of caregiving. My work to date has focused on observations of the patient's illness experiences, but less on parental caregivers' personal experiences coping as caregivers. Prior work by Kaziunas et al. found that parents face heavy emotional burdens and intensive information work as they transition to the role of caregiver [188]. While understanding parents' felt experiences would help us learn and account for their needs related to documentation, it will be important to prioritize technology design that does not add to their information burden. In my conversations with a patient family in S5, I learned the need to provide support for multiple caregivers who—such as in the case of dual income families—share the same responsibilities for caregiving and work. Both parents told me that they quickly coordinated the handoff of diaries as they shifted their caregiving responsibilities from one to another. I took note of this observation to design for multiple caregivers by enabling them to switch accounts to log entries.

7.7 G7: Attend to Adverse Events

According to Food and Drug Administration, an adverse event is any undesirable experience associated with the use of a medical product in a patient [189]. Treatment receiving patients may, on certain circumstances, experience a severe side effect as a result of a complication caused by their inability to tolerate their prescribed dosage of medication.

- **Communicate adverse event to patients and provide relevant resources**.

In developing CO-OP, our research team had to navigate the potential consequences that may occur in case of an adverse event. We realized that as researchers, we carry partial responsibility to ensure the patients' safety, and that in the design of technology, there is a critical need to determine when a patient is unsafe. To understand the risks that follow from complex treatment regimens, I collected patient education resources from CHOA and identified potential adverse events as well as established clinical protocols for each event

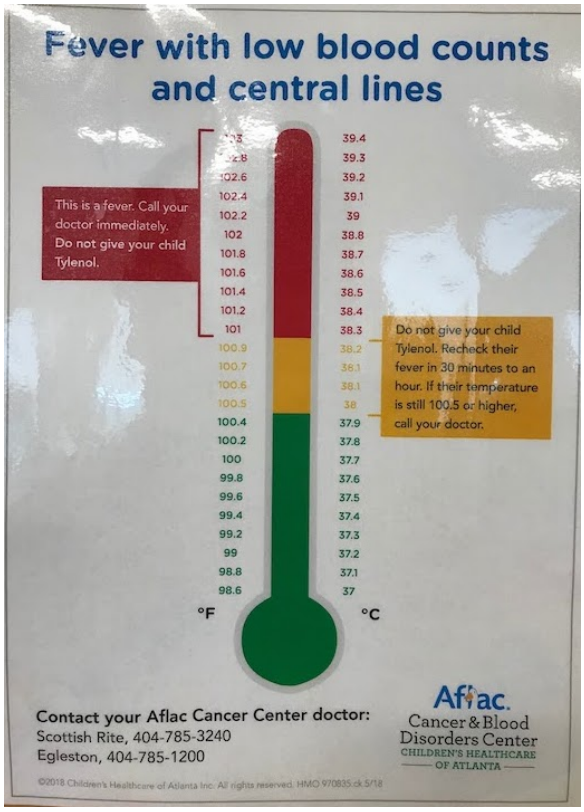

Figure 7.2: Image of Hospital Protocol for Fever Adverse Event. Photograph taken at CHOA's Cancer Clinic.

through several discussions with several doctors and nurses. These adverse events included vomiting, high fever, severe pain, and depressive symptoms. Through these discussions, I learned about the appropriate clinically recognized thresholds for each event to escalate the significance of the event within the CO-OP system. For example, in the case of high fever, the cancer clinic at CHOA has its own established protocol for patients and caregivers to call in for emergency admission (Figure 7.2).

A primary goal that I decided to support through technology is to have a system in place that can automatically detect instances of patient responses that deviate from a designated threshold value for an adverse event. The system can then communicate the significance of the event to the patient through an interface that requires them to read and confirm their receipt of information. In CO-OP, there are four modal popup screens that only appear in the adverse event scenario. Each screen contains information about the severity of the

patient's health status, encourages patients to talk about their health status to immediate family caregivers, and provides patients with relevant resources.

CHAPTER 8

CO-OP SYSTEM DESIGN

Figure 8.1: CO-OP Tablet Application.

I designed the CO-OP[1] system to provide a means for both patients and family caregivers to collaboratively contribute their observations (in-situ) of the patient's daily illness experience. CO-OP is an interactive tablet mHealth application that integrates self-reported observations with passively collected data such as tablet usage, location, and social context. The application can generate rich perspectives on the patient's illness experiences, including captured media data and collateral information about when and where side effects are occurring.

In designing CO-OP, I followed a user-centered design process that spans several design studies (S3–5) and collaborations with an Android Operating System developer[2].

[1]The acronym CO-OP derives from **CO**llaborative **O**bservations of **P**atients' Daily Living

[2]I led the design of illustrations, front-end user interface, and an automated mEMA system via REDCap. Jung Wook Park, a Georgia Tech PhD student, led the software engineering efforts.

8.1 Design Process

Over the course of two years, I iteratively evolved the design and form factor of the visual illustrations by engaging and collaborating with adolescent cancer and lupus patients and their family caregivers. The insights from prior studies also informed the final structure and UI flow of the CO-OP system. The figures below show the iterative nature of the design process that led to the final design of digital artifacts for mobile interaction.

Figure 8.2: Iterative Design of Illness Representations. Left: Hand-drawn paper sketches. These sketches were used in the Co-design study (S3) as cards; Middle: Computer-assisted vector outlines. These illustrations were used in the diary study (S5) as stickers; Right: Pixel-perfect vector renderings. These illustrations were used in the the design of CO-OP system as digital buttons.

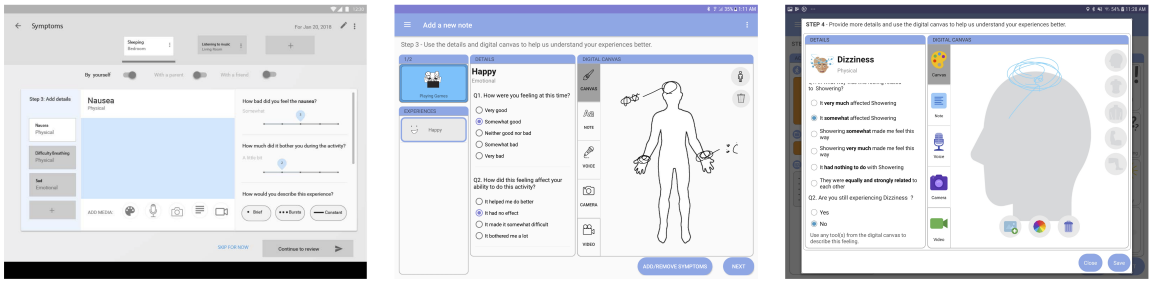

Figure 8.3: Iterative UI Design. The design of the Digital Canvas feature has evolved over time. A: Initial UI Mockup; B: UI Version 1; C: Final UI

8.2 System Hardware and Technical Specifications

8.2.1 Hardware

The CO-OP system is developed for the Android 9.0 Pie mobile operating system. The application is optimized to run on Samsung's flagship tablet, Galaxy Tab S3 (9.7 inch), which are provided to participating families, and which supports multiple on and off-screen stylus operations through its S-Pen Stylus. I chose to use the Galaxy Tab S3 tablet device in my study based on several factors.

Figure 8.4: Samsung Galaxy Tab S3 (9.7 inch) and S-Pen stylus.

Stylus

The amount of detail in sketch drawings produced by patient participants from the diary study (S5) pointed to a critical need to support their ability to flexibly express daily illness experiences. The S-Pen Stylus supports precise writing and various annotation activities with state-of-the-art sensor technology (0.7mm tip and 4096 levels of pressure sensitivity). Thus the stylus' versatility has been a major factor that I considered while deciding among various off-the-shelf products.

Device Form Factor

Both the co-design (S3) and diary studies (S5) provided insights about the need to depict micro-level details about each activity and illness experience. Yet, in testing a pocket size diary with healthy high school students, I found that participants had trouble reading text labels discerning the significance of each illustration. This meant that the detailed representations in each of the illustrations required a large display size by default.

In order to fully leverage patients' recognition (rather than recall) of illness experiences, I needed the device to be able to display the full list of activities and emotional and physical experiences in one view without requiring the user to perform excessive scrolling actions or access several pages to see the full list.

In summary, I decided to choose a tablet form factor (over a mobile phone, for instance) because it was important to accommodate their need to flexibly express their illness experiences with a large screen size that would not sacrifice the legibility and resolution of the illustrations.

8.2.2 System Architecture

The CO-OP system application is designed to support both passive and semi-automated approaches to sense patients' illness experiences. Approximately every two minutes, the application packages a combination of data collected through passive sensors and patient and family self-reports, and creates a single usage log dB file (along with a folder containing user-contributed media data) that is stored on a HIPAA-compliant enterprise Dropbox server licensed by Georgia Tech.

Passive Sensors

Like most android-powered devices, Samsung's Galaxy Tab S3 has built-in sensors that measure motion, orientation, and various environmental conditions. These sensors can detect the devices' movement, physical location, and changes in the ambient environment

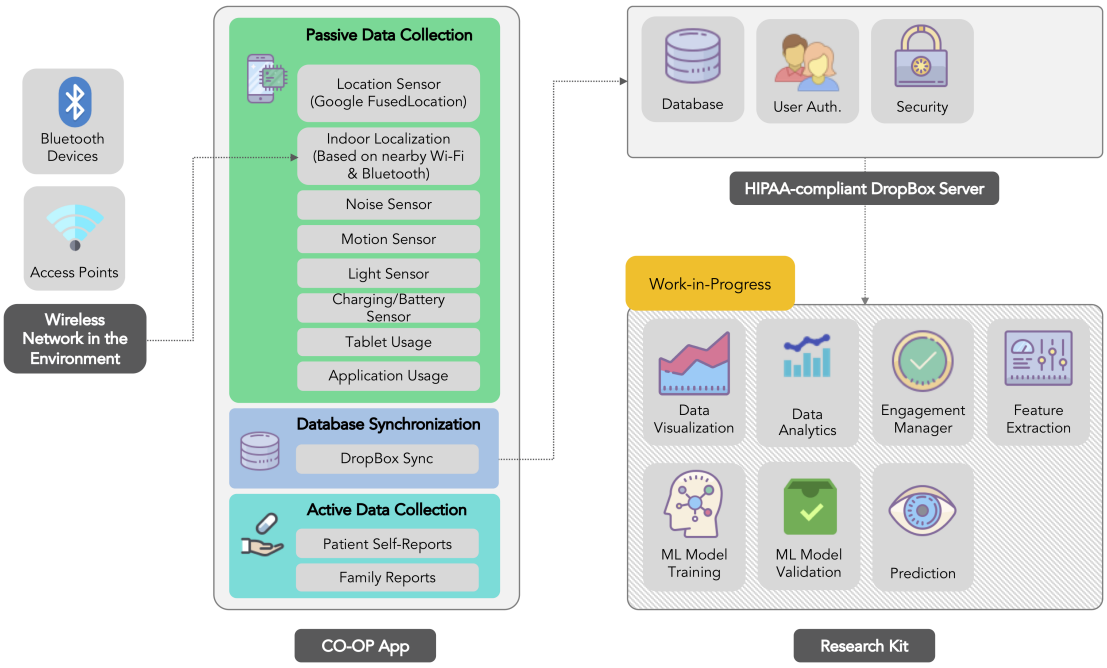

Figure 8.5: CO-OP System Architecture.

near a device and provide raw data from which researchers can make further inferences about the user's behavior and usage pattern. In developing CO-OP—for every 10 seconds and whenever the device has continuous connection to Wi-Fi—we included the ability to passively detect the following properties of the device:

- **location**, through longitude and latitude sensors
- **indoor location**, through data triangulation of nearby Bluetooth and Wi-Fi Service Set Identifiers (SSID) and relative received signal strength (RSSI)
- **ambient noise**, through microphone
- **motion (shake/tilt)**, through accelerometer, gravity and gyroscope sensors
- **ambient light level**, through a light sensor

- **charging state and battery level**, through the Android OS battery manager
- **tablet usage (e.g., power on/off status)**, through Android OS management software
- **application usage**, through Android OS management software

8.3 Design Features

Patient and caregiver versions of the CO-OP application support two main features: entering and reviewing notes. The caregiver version includes the ability to switch between different family user profiles. Figures 8.6 and 8.7 illustrate detailed user flows in which each patient or family member is expected to interact with multiple design features throughout the application. Below I describe each design feature that is included in the most recent development of CO-OP application.

- **Add a Note**: to start entering morning, afternoon, or evening notes, users will be asked to tap the button: 'ADD A NOTE FOR TODAY'. The message on the home screen will allow users to see how many notes they have entered for the duration of the study. The system will send two text reminders a day to help users remember to enter these notes.
- **Select Activity**: users can select one or more recent activities that they completed in the past 5-6 hours. For each activity, they will be prompted to indicate how easy or difficult it was to perform each activity.
- **Create Custom Activity**: if an activity does not match any of the existing activity categories, users will have the option to register a new custom activity and name it accordingly.
- **Indicate Activity Context**: users are asked to indicate the time, duration, place and person they were with for the activity recently completed. Caregivers should indicate whether they were together with their child.

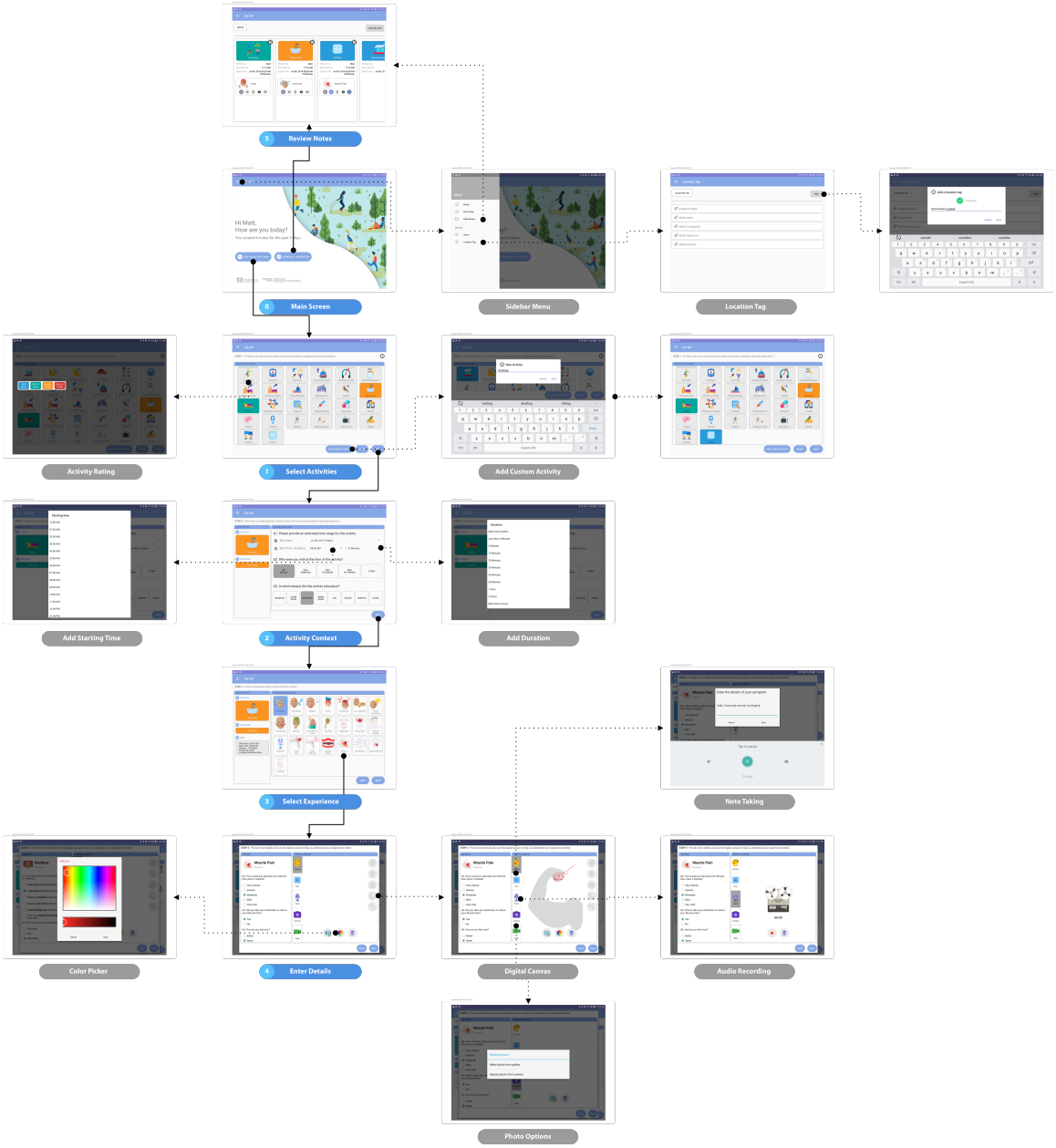

Figure 8.6: CO-OP Patient User Flow.

- **Select Experience**: users are asked to select one or more experience stickers to associate with the chosen activity

- **Enter Details**: users have the option to answer questions about the selected experience and use the digital canvas to better express their feeling related to the selected experience.

- **Digital Canvas**: users can sketch, write a note, record a voice, import/take a photo or

Figure 8.7: CO-OP Parent User Flow.

video. A stylus is provided for easy sketching and note taking. A color swatch and multiple drawing templates representing different body parts are provided to scaffold the skeching process.

- **Copy or Skip Experience**: users have the option to copy their previous choice of experience if it lasted for the duration of more than one activity. They can do so by tapping the button: 'COPY FROM PREVIOUS ACTIVITY'. Alternatively, they may choose to skip selecting an experience if they did not feel anything.

- **Review Notes**: All entered notes can be accessed from the home screen. Users can

review and modify previously entered notes if they need to add more details or change their response.

- **Location Tag**: In order to calibrate for the indoor localization feature, users need to add a new locations. A Location Tag can be accessed from the side menu. Users will be asked to provide the name of the location and wait until the scan has been completed.

- **Switch Accounts**: Family members can switch accounts by selecting 'Switch Account' from the side menu. To add a new user, they must select 'ADD A USER'

The design of these features are informed by the design guidelines, as I have mentioned in Chapter 7. They are also in line with the five narrative features which are essential for supporting patient-authored illness narratives. Table 8.1 below illustrates the relationship among the five narrative features and features that have been designed for CO-OP.

Table 8.1: Five narrative features of medicine (adapted from Charon et al. [67]) and their relationship to CO-OP features.

	Expected Role of Technology	**CO-OP Features**
Temporality	Guiding patients' attention to support chronological story-building	Daily reminders, Indicate activity context
Singularity	Providing effective scaffolds for patients to capture and learn about illness experiences	Digital canvas
Causality	Intuitively and visually representing patient collected details of events as a cohesive story to support causal inference.	Review notes
Intersubjectivity	Guiding patients to construct daily stories through user friendly interface and interactive feedback.	Add a note, Select activity, Select experience
Ethicality	Supporting patients to translate their perceptions, sensations and thoughts into language tailored to their cognitive and communication abilities.	Digital canvas, Enter details

8.4 Pilot Study: mHealth Probe

8.4.1 Introduction

I deployed CO-OP as a mHealth probe to investigate how we can best engage adolescents and parents in the design process to create meaningful representations of the patient's illness experience. The goal of mobile ecological momentary assessment (mEMA) is to repeat sampling of participants' current activities and experiences in near real-time (through daily prompts sent at different time periods), in their natural environments. Understanding patients' activities and illness experiences in their everyday living is critical to evaluate and determine appropriate techniques for eliciting illness experiences that unfold in various contexts of patients' daily living.

This pilot study aimed at examining adolescent patients' self-efficacy for communicating and managing their illness experience before and after the 21 day mEMA period. I asked the following question to guide this research. Will patients (who are engaged in their daily design work) become confident in their ability to manage and articulate their illness experience?

To address the mentioned question, I drew from the following data sources: mobile sensor data, daily mobile ecological momentary assessments (mEMA), pre/post surveys Data collected includes daily tablet survey responses—including open- and closed-format responses, usage log data, and user-contributed photo, audio, video and sketches—and audio recordings of the design sessions.

8.4.2 Method

Recruitment

For this pilot study, I recruited three (M=2; F=1) adolescent patients (two with cancer and one with lupus) along with their family caregivers at CHOA's cancer and rheumatology clinics who are living within a 25 mile radius, receiving routine treatment, have a mobile

phone, and expected to return to the clinic within three to four weeks for follow-up visits.

Nurse practitioners and clinical research coordinators screened for eligible patients who fit the inclusion/exclusion criteria, and communicated information about eligible patient participants' visitation schedule through CHOA's hosted REDCap software[3]. Once screened for eligibility, the attending physician or nurse practitioner first solicited patient families' interest to hear about the study. Recruitment for the pilot study began in July 2019 and ended in September 2019.

Surveys

After obtaining consent from the patient and parent, I deployed an online survey via a tablet computer using the REDCap software (see REDCap Survey). I collected participant responses to various survey measures, including demographic information, technology use, health literacy, healthcare utilization, communication with physician, pediatric quality of life, self-efficacy for managing chronic disease, communication self-efficacy, and parental caregiving burden. Participants who did not have the time to complete the surveys in person were provided with a secure web-link (via REDCap) to their mobile phone via text messaging to complete the remaining surveys in their own time until a subsequent onboarding in-person meeting. Once they have completed the mEMA portion of the study (21 days after initiation of the mEMA), participants were again provided with a secure web-link (via REDCap) to their mobile phone to complete all . Table 8.2 shows a full list of survey instruments employed in the study.

Baseline surveys consisted of Demographic Questionnaire and Household Technology Use, and a series of validated instruments, including the Health Literacy Assessment Scale for Adolescents (HAS-A) [190], Health Care Utilization [191], Communication with Physicians [191], Pediatric Quality of Life (PedsQL) Cancer [192] and Rheumatology [193] Modules (3.0), Collaborative Parent Involvement Scale (CPI) [194] (Appendix A.3),

[3] At the end of each week, clinicians received a secure web-link via email to access data forms that request information about the patient's visit appointment (see Appendix **??**)

Table 8.2: mHealth Probe Pilot Study Activities. mEMA=Days(n) in Mobile Ecological Assessment. x indicates study activities completed by the researcher (R), child (C), or parent (P). *=Early Exit Questionnaire is triggered only when participants indicate their preference to drop out of the study.

Phase	Context	mEMA	R	C	P	Study Instruments
Enrollment	Clinic		x			Demographic Questionnaire
	Clinic (or online)				x	Demographic Questionnaire 2
				x	x	Household Technology Use
				x		Health Literacy Assessment Scale
					x	Health Care Utilization
				x	x	Communication with Physicians
				x	x	Collaborative Parent Involvement Scale
				x	x	PedsQL Cancer (or Rheumatology) Module
				x		Self-Efficacy for Managing Chronic Disease Scale (Pre)
				x		Communication Efficacy Scale (Pre)
					x	Parent Experience of Child Illness (Pre)
Onboarding	Home	Day 0	x			Pre-Interview Guide
						Onboarding Session Guide
Week 1	Home (or other)	Day 6	x			5 Day Compliance Calculation Form
		Day 7		x	x	Week 1 Check-in
Week 2		Day 14		x	x	Week 2 Check-in
Week 3		Day 21				-
Exit (mEMA)		Day 21+		x		Self-Efficacy for Managing Chronic Disease Scale (Post)
				x		Communication Efficacy Scale (Post)
					x	Parent Experience of Child Illness (Post)
				x	x	CO-OP Exit Evaluation
		Day X		x	x	*Early Exit Questionnaire
Exit (Study)	Home or clinic		x	x	x	Post Interview Guide
			x			Exit Compensation Calculation Form
			x			Compliance Calculation Form

Self-Efficacy for Managing Chronic Disease Scale (SEMCD) [191], Parent Experience of Child Illness (PECI) [195] and Communication Efficacy Scale (Appendix A.1). I designed the Communication Efficacy Scale (CES) based on Bandura's guide for constructing self-efficacy scales [196]. The questions were adapted from the HAS-A communication construct [190] (Appendix A.2).

Exit surveys included post measures of SEMCD, PECI and CES, CO-OP Exit Evaluation (Appendix A.5), and Early Exit Questionnaire. I adapted the Exit Evaluation survey from Basch et al.'s work on Symptom Tracking and Reporting for chemotherapy [197].

The Early Exit Questionnaire was sent to participants only if they dropped out of the study during any phase.

Onboarding

I scheduled an in-person meeting in the participants' home to conduct a 15 minute interview to clarify participant responses to the CES instrument, and a 30 minute onboarding session. I structured the onboarding session based on Heron et al.'s guideline for conducting mEMA studies with youth [198]. Topics covered during the onboarding[4] included the study purpose, expectations for participation, information about passively collected data, protection of their confidentiality, compliance, compensation scheme, and tutorials for the tablet setup and CO-OP application. After the onboarding session, I provided two tablets to the family participants—one for the patient and another for family caregivers.

mEMA and Mobile Sensor Data

The typical time frame between visits during treatment falls within two to four weeks. For this pilot study, I deployed two tablets in the participants' home over a 21 day period. I collected a wide range of tablet mEMA responses—including open- and closed-format responses, usage log data, and user-contributed photo, audio, video and sketches. mEMA entries (on tablet device) were expected to take about 10–15 minutes to complete each day. Tablet usage and interaction data included response time, access location, battery level, battery charging status, Wi-Fi and bluetooth scan result, audio noise level (decibel), light level (illumination), activity (standing, walking, running, etc.), application usage (foreground apps), and device usage (screen on/off). I was able to access tablet usage and interaction data to track participant compliance rates with daily mEMA prompts, be able to follow up with non-complying participants in the early phase of deployment, and support data triangulation between self-reported and tablet usage/interaction data.

[4]Onboarding slide deck is included in the supplementary files

Compliance

Participant compliance was calculated based on established standards for calculating EMA compliance proposed by Stone et al. [199]. To encourage compliance with the mEMA protocol, three short text message prompts were sent to the participants' mobile device in the morning (8am), afternoon (4pm) and evening (8pm) times. The text messages were scheduled and sent from REDCap using its automated survey invitation feature. I used a 90 minute liberal window to calculate participant compliance to a reminder signal. For example, mEMA responses recorded within 90 minutes of the text message prompts were only considered compliant and included in calculating the final compliance rate. Compliance was calculated based on the following equation:

$$Compliance = \frac{\text{Sum of Entries}}{\text{Sum of Possible Entries}}$$

I cross-referenced participants' usage log data to fill out the Compliance Calculation Form, which generated the results of compliance calculations. Summary results of participant compliance rates over the three week period are listed in Table 8.3.

Analysis

Three patient-parent dyads completed the pilot study to date, and my analysis focused on comparing and contrasting patient and parental caregiver interactions with the tablet, responses to surveys, and responses in debriefing interviews. I inductively coded all transcripts, focusing on adolescents' and parents' experience with the mEMA study and their perspectives toward use of the deployed technology. Due to the low-powered nature of the pilot study, I employed descriptive statistics and qualitative analysis to contextualize the findings. In an adequately-powered, large scale implementation of this study[5], I expect to use a paired sample t-test for comparing the mean difference of total value for validated in-

[5]I looked to [200] and [201] to determine the appropriate statistical analysis methods for a large scale study.

struments, and Wilcoxon signed-rank test for comparing differences in individual response items within each instrument.

Table 8.3: Pilot Study Participant Demographic Information and Summary of Results

		C1	P1	C2	P2	C3	P3
Demographics	**Race**	African American		Caucasian		African American	
	Diagnosis	Cancer		Cancer		Lupus	
	Education		Some College		College		Vocational/Technical
	Marital Status		Separated		Married		Living as Married
	Employment Status		Employed		Employed		Unemployed
	Household Income	$25,000 - $34,999		$150,000 or more		Less than $25,000	
	# of Household Members	5		5		3	
Household Technology Use	**Tablet**	iPad		iPad		N/A	
	Wearable	N/A		N/A		N/A	
	Health monitoring device	Scale		N/A		BP monitor, scale	
	AI conversational agent	Google Home		Amazon Echo		N/A	
Communication with Physicians (0-5)	*(high is better)*	1.33	3.33	2.33	4	2	2.33
Healthcare Utilization	**# of Physician visits**	20		3		9	
	# of ER visits	2		1		2	
	# of Overnight stays	15		1		2	
	# of Total nights stayed	30		10		9	
Health Literacy Assessment (0-4)	**Communication (high if >14)**	20		16		19	
	Confusion (high if <8)	14		3		2	
	Functional (high if <12)	9		2		2	
PedsQL (0-100)	*(high is better)*	75	50	49.07	41.67	-	-
Collaborative Parent Involvement (1-5)	*(high is better)*	1.42	5	5	2.83	2.58	4.33
CO-OP Exit Evaluation (1-4)	*(high is better)*	3.7	3	2.3	2.73	3.7	3.8
mEMA Compliance Rate	**Week 1**	100%	100%	47.62%	19.05%	42.86%	9.52%
	Week 2	33.30%	47.62%	0%	0%	23.81%	9.52%
	Week 3	0%	0%	0%	0%	28.57%	14.29%
	Final	44.40%	49.21%	15.87%	6.35%	31.75%	11.11%

8.4.3 Findings

Below, I describe preliminary findings from the pilot study, drawing attention to interview transcripts that show participants' reactions to their use of CO-OP, tablet usage data, and results of the survey measures. In elaborating on the findings, I refer to three child (C) and parent (P) dyads: CP1, CP2, and CP3. C1 (M; 11 years old) and C2 (M; 15 y.o.) are cancer patients and C3 (F; 17 y.o.) is a lupus patient.

Tablet Usage Over Time

The final compliance rates for all participants over the 21 day study period were, C1 (44.4%), P1 (49.21%), C2 (15.87%), P2 (6.35%), C3 (31.75%), and P3 (11.11%). While

most families were compliant in the first week, their compliance rates significantly dropped during and after the second week of the three week study. Only CP3 mantained a steady engagement throughout the study. In the following section, I describe preliminary qualitative findings that provide context for these compliance rates.

Challenges using mHealth during School and Work Hours

when asked about their experience responding to text message reminders, all patients and parents appreciated the role of reminders, which helped them remember to document their observations of the illness. However, they also indicated that the reminders, while helpful, distracted them from important tasks. For example, the morning reminders at 8am most conflicted with parents' schedule at work or patients' schedule at school. P1 said, "*He [C1] was at school and I was at work so the timing was just really off. I think that you guys should just let the people enter it when they enter it. Because putting them on a timeline when they have jobs and school, that was inconvenient.*" Certain schools had strict policies against using mobile technology, which made it difficult for adolescents to carry and log their illness during school hours. C2 shared this concern, "*[...] especially in high school because they don't let you on your phones very much*" Even after regular school hours, there were moments in which documentation can be a burdensome task for patients. While C2 carried the tablet to his friend's house, he did not like the experience of needing to respond to the reminders in the middle of a group activity. He continued, "*I had to stop. If I'm at my friend's house we had to stop what we're doing so I can log stuff. Sometimes that gets in the way, and yeah.*"

The fear of facing cancer-related stigma also acted as a potential barrier for patients. One patient, C1, carefully shared why he was not able to use the tablet at school. He elaborated on his experience suffering from the negative effects of stigma, and said that "*they took my hat off and those two were like 'I think he has cancer'. So when I walked off the bus they tried to snatch it off. But I had it on tight so nobody could take it off.*" In further

conversations with him, C1 told me that using the tablet outside to manage and share his feelings would further perpetuate this stigma.

Perceived Value of mHealth Technology

Participants in this study also provided many useful insights about the value that an mHealth tool could provide for their engagement in care processes and health management. For example, P1 and P2 both told me that the daily mEMA questionnaires that they answer through the mHealth probe already resemble existing clinical instruments that they are required to fill out upon each visit. P2 suggested that mHealth tools can provide huge value for patient–doctor communication if it provided the means to complement or replace their need to fill out clinical questionnaires in order to reduce wasted time in the waiting room. She remarked, "*When we go to clinic we fill out a thing [symptom inventory] when we're being admitted. So if that information [CO-OP data] was [...] automatically pushed to the doctors, I think it would be helpful in communicating with the doctors just because, as a parent and a caregiver, it is sometimes hard to keep track of days.*"

All patient families told me that the biggest direct clinical impact and value they expect from the mHealth technology is having the ability to change medication or adjusting the dosage. C3 told me about the significance of documenting her responses to medication used in treatment, and said "they [clinicians] decrease my medicine, increase it." However, patients emphasized the need for buy-in from clinical caregivers. One of the reasons that led to C2 and P2's low engagement from the mHealth probe was the lack of continuity of care that followed from the time and effort that they put into documenting her observations. In particular, P2 lamented that clinicians did not refer to the logged data during C2's visits to the doctor, and suggested a strong need for them to review and use the health data—that she and her son collected together—in clinical conversations. She continued, "*I don't think what we logged helped us with the doctors, because we weren't referring back to it when we are talking to them. I think it's probably better if we logged it and then they [doctors]*

talk to us about it so that we know what's important to them and what's not as important." P3 commented that clinicians' engagement was critical in case of an outbreak of adverse events between scheduled doctor appointments. "There have been times she [C3] had an allergic reaction. Then she doesn't see the doctor once a month. So sometimes she doesn't have an appointment till later on, the rash may have gone away. And they are not able to see what she was describing."

The lack of buy-in from clinicians also influenced patients' motivation to engage in daily design activities. C2, who produced over 24 sketches of his illness experiences that include pain, commented that he would have elaborated more details if the drawings were to be sent to the doctor. C2 told me, "I don't think I would go into that much detail I'd just say that it was hurting [...] If this was an actual thing and it was going to the doctors, I'd probably have to be more specific for it."

Survey Results

In designing this study, I expected that patients who maintain higher engagement with the mHealth probe would have increased their confidence in their ability to manage and communicate about their illness experience. The pre- and post-survey results, however, indicated mixed responses. For example, while C2 produced the highest number of sketches, and while his SEMCD score increased after the pilot, his CES score also decreased.

In addition, I also expected that parents would experience lower emotional burden after the study period. Results of the PECI surveys showed that P2 and P3 both experienced decreased emotional burden of caregiving after using the mHealth probe. However, since this is a pilot study, I assumed that no conclusions can be drawn from three participant responses.

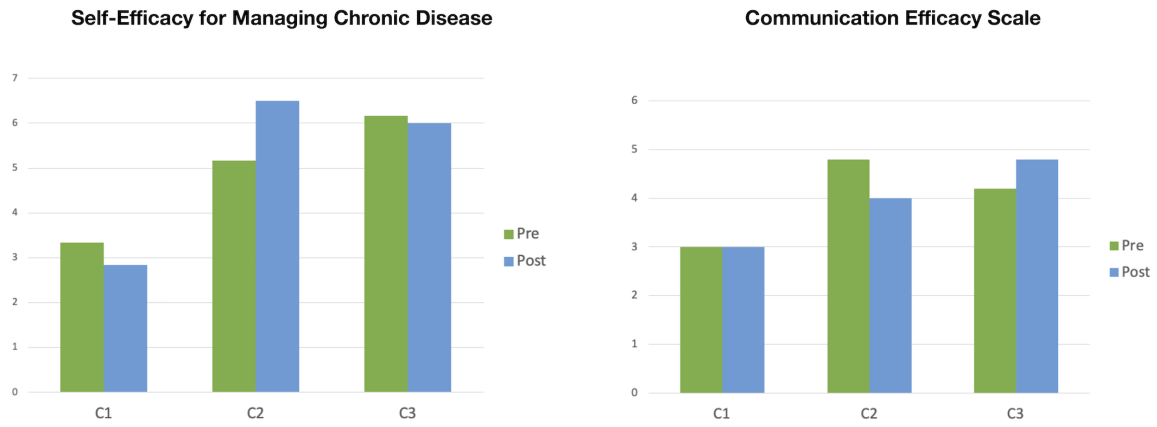

Figure 8.8: (Left) Self-Efficacy for Managing Chronic Disease Scale. (Right) Communication Efficacy Scale. Higher value means child patient felt more confident about their ability to manage illness or communicate with their doctor.

8.4.4 Discussion

Early results from the pilot study inform ways in which I can modify the protocol to enhance future participants experience in a subsequent large mHealth study. By uncovering participants' reactions to the daily text reminders, I learned about the challenges of engaging users outside of their home. All participants experienced barriers using the mHealth probe at school or in the workplace, in which the use of mobile devices are not considered a socially accepted behavior. Stigma was also an important factor that discouraged patients from taking the tablet outside.

These findings provide insight into designing reminders in probe-based deployments for adolescent and parent caregivers. Prior to deploying mHealth technologies, it will be important to have discussions with participants to incorporate their preferred times for engaging with the mobile EMA protocol. Another consideration is to avoid competing with participants' routines that require their full attention, such as school and work hours as well as other family-centered routines (e.g., dinner). Participants in the pilot study preferred early morning and evening times as potential opportunities to engage them in research and design activities.

Adolescents and their parents saw potential value in using the mHealth technology

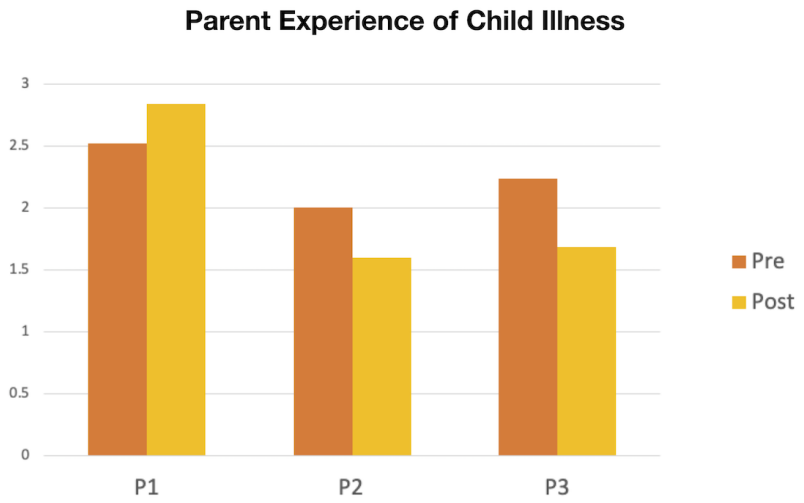

Figure 8.9: Parent Experience of Child Illness. Lower value means parent experienced less emotional burden.

to integrate and complement existing care processes. This included filling out standard clinical measures of patients' illness experience (such as Review of Systems) and providing them a means to quickly communicate adverse events to care providers between scheduled doctor's appointments. However, without buy-in and engagement from clinicians to use their data in patient-doctor encounters, participants showed little enthusiasm about their use of mHealth technologies between visits to the hospital.

Observing and documenting illness experiences requires significant amount of participants' attention, time, and physical labor. The low compliance rates show that participants did not fully engage in the mHealth study even if they were provided monetary compensation for participation. In order to fully engage patient families in their care processes, it will be important to reflect their values as patients and caregivers in the design of the research protocol. For instance, asking clinicians to review patient- and parent-collected data prior to the visit, and including (in the protocol) observations of their interaction that stem from the use of PGHD could improve patient families' perceived value in participating and engaging in long-term mEMA studies.

CHAPTER 9

IMPLICATIONS FOR DESIGN, PRACTICE AND FUTURE WORK

My dissertation has looked at supporting adolescents' shared health management and participation in care with their parents by designing a mobile health system that engages patients with their personal health data. My contributions to HCI research (which are outlined in Chapter 10) provide the necessary context to discuss design implications and future research directions in the design space for intelligent and collaborative mobile health experiences.

9.1 Implications for Design

9.1.1 Designing to Capture the Holistic Experience

The adolescent population in my studies are chronically ill patients in need of specialized care by their family and clinical caregivers [202]. However, outside of the clinic and responsibilities for illness management, they are also ordinary human beings who go to school, socialize with friends, and have career aspirations. I have come across many examples in my research that show ways in which adolescents are too often addressed in relation to their disease. For example, in S1, some adolescents told me that they grew tired of responding to parents who would ask questions about their health status on a daily basis. One doctor told me that, besides symptoms and side effects, school attendance and grades are also important indicators of health, and deserves more attention (S3). To engage adolescents, there is a better need to address them as a 'whole person', see illness as a unique function of their biopsychosocial experience, and capture their holistic experience as an independent human being.

Illness Narratives

Illness narratives are autobiographical and biographical stories told by patients and family members about how they perceive, respond to, and live with the patient's illness experience (see Chapter 3 for a detailed description of illness narratives) [64, 65]. As such, the concept of narratives (or storytelling) lends itself to giving patients and family members an organizing frame of reference to address the 'whole person'.

I drew from the idea of illness narratives conceived by medical sociologists and literary scholars, and applied human-centered approaches to design a patient-centered mobile health technology for adolescents and their family members. While illness narratives and the features of narrative medicine have been heavily studied by medical professionals, and produced knowledge to support their practice, very little was known about what patients and family members can contribute to the practice of clinical communication based on narratives. Findings from my research complement existing knowledge about narratives by providing insights toward eliciting patient stories and engaging patient families to construct and build on their stories before they talk to a clinical professional.

For example, my research focused on understanding ways to elicit adolescents' lived experience. In S3, I learned that there is a need for technology to scaffold the process of encoding and articulating illness experiences through representation of context surrounding adolescents' symptomatic responses—specifically to support depictions of how symptoms affect patients' ability to engage in daily activities. This need was also echoed in my conversations with clinicians (S3 and S4), who saw such engagement as fundamental to adolescents' quality of life. However, quality of life assessments in current medical practice still rely on validated instruments that use structured numeric scales [119, 122]. My research thus focused on exploring opportunities for technology to support adolescents' in constructing their own illness narratives in ways that can provide needed information to contextualize the numeric representations.

Table 9.1: Five narrative features of medicine (adapted from Charon et al. [67]) and expected roles of clinicians, patients, and technology. *My contribution includes the expansion of narrative features to include respective roles of patients and technology.

	Clinician	**Patient***	**Technology***
Temporality	Being aware of the patients' time and taking time to listen, recognize and care.	Taking time to recognize, capture, and reflect on illness observations.	Guiding patients' attention (e.g., through reminders) to support chronological story-building
Singularity	Recognizing patients' experience as unique instead of recurring, replicable experiences across human bodies.	Learning to attend to unique illness experiences and observe them.	Providing effective scaffolds for patients to capture and learn about illness experiences
Causality	Corroborating patient-contributed stories with clinical data to determine causality.	Gathering and piecing together details of events together as family.	Intuitively and visually representing patient collected details of events as a cohesive story to support causal inference.
Intersubjectivity	Listening to and eliciting patients' first person stories to support personal exploration and discovery of what's meaningful to them.	Interacting and communicating with family members so they can help build a cohesive narrative.	Guiding patients to construct daily stories through user friendly interface and interactive feedback.
Ethicality	Being equipped with the ability to attend and respond to patient contributed stories in a patient-centered manner.	Using personally meaningful and adaptive representations of their illness experience to articulate the subjective experience.	Supporting patients to translate their perceptions, sensations and thoughts into language tailored to their cognitive and communication abilities.

Self-tracking vs. Narratives

A key distinguishing feature between self-tracking and illness narratives is that self-tracking is often concerned with, and emphasizes the quantification of various indicators of the patient's health status, including the frequency, severity, and temporal aspects of the signs of disease, responses to treatment, and overall physical and emotional well-being [156]. This quantitative representation of the patient's health status, along with accompanying graphical visualizations, provides a common point of reference (or "boundary object") between patients and practitioners, allowing both to make useful inferences by making comparisons

across time as well as similar patient groups [203]. Illness narratives, on the other hand, emphasize the ”singularity” or uniqueness of the individual patient's experience with their illness [64].

Information about the patient's unique autobiographical experience is only accessible to them, and it is unpacked as a story (or multiple connected stories) in the context of patient-doctor encounters. Doctors are professionally trained to elicit and capture these patient stories in the form of a two-way dialogue, but they may have difficulty in capturing these stories if the patients cannot articulate them. Specifically, not all patients are trained to provide a well-articulated, and fully-descriptive narrative of their illness experience. Moreover, while quantitative measures might sufficiently help patients express the severity of frequency of these feelings, they fall short in helping patients reach conclusive evaluations of co-occurring symptoms.

Media based elicitation could help patients better evaluate and clarify subjective, and often vague feelings. A central finding in S3 and S5 is that young patients can articulate these feelings through the use of technologies that support flexible and rich means for expressing their holistic experience. Media technologies, which are already built into most mobile devices that exist today, have played an instrumental role in supporting young people to observe and attend to their unique lived experiences and freely express their singularity. In S5, I explored the intersection of supporting both objective tracking and momentary reflection of one's health status through medium probes [204]. For instance, paper diaries (in which they documented the type and frequency of feelings as well as the associated subjective ratings) and media-based probes helped patients articulate their personal illness narrative around objective data in ways that support their expression.

Role of Technology in Narratives

Through my research, I discovered various roles that technology can play in supporting patients' rich constructions of their illness narratives, but also facilitating patient commu-

nication with clinicians (See Table 9.1).

I designed a story-boarding technology in the form of CO-OP to play a huge part in guiding patients to become better storytellers and engaged participants during (and in-between) clinical encounters. This meant that technology should be able to: 1) guide adolescents' attention to support their chronological story building process, 2) provide effective scaffolds so they can capture and learn about their illness experience, 3) intuitively (graphically) represent self-reported illness events as a cohesive story to support causal inference, 4) guide their construction of daily stories through interactive feedback, and 5) support adolescents to translate vague, unresolved feelings and thoughts into concrete and expressive language that is tailored to their cognitive and communication abilities.

In order for technology to play its part, adolescent patients, their family members, and clinicians will also need to work together and contribute to building a comprehensive narrative of the patient's illness experience.

9.1.2 Supporting Private and Collaborative Mobile Health Experiences for Families

Family members provide the daily context for adolescents' illness management, and patients will need to collaborate with their family caregivers on a range of health management tasks to make progress toward successful treatment and recovery [134]. My research suggests the importance of maintaining a careful balance between supporting both adolescents' privacy needs as well as families' caregiving needs in order to establish healthy collaborations that will lead to better assessment and care of the patient's ongoing illness.

Need for Private Mobile Health Experiences

Illness management plays a central role in the care of complex chronic illness, but, in the pediatric setting, reported assessments of the patient's health status are often one-sided: parental caregivers still assume the role of symptom reporting [126]. Yet, plenty of evidence point to statistically significant disagreement between patient and parent assessments

of the patient's illness experience, suggesting that symptom data reported by parents may not adequately represent the patient's true felt experience [114, 116, 117].

Instead of relying on caregiver-reported assessments, illness management should be patient-centered, and it will be important to support adolescents to self-report their own assessments of their health status. In reporting their health status, I learned that adolescents required a private line of communication to talk about sensitive topics (e.g., reproductive ability) or an intense physical experience—in order not to worry their parents (S1). This need for privacy however created tensions between patients and parental caregivers. While adolescents value private experiences for documenting and reporting their illness, family caregivers expressed a huge need to understand their child's illness experience. When understanding was not an option, caregivers relied on very limited, and often inaccurate, information (subtext based on patient's posture or facial expressions) to reach a close approximation of how the patient felt.

Need for Collaborative Mobile Health Experiences

By exercising care in conducting privately held interviews (S1 and S2) and dyadic interviews (S3, S5, and S6), I was able to maintain a careful balance between understanding both private and collaborative needs among adolescents and their parents. My studies point to various ways in which adolescents and families have coordinated collaborative efforts to carry out communication about sensitive and mundane aspects of the patient's daily illness experience. For some families, emotionally sensitive discussions were best carried out after some passage of time and outside of the typical face-to-face context. Other families leveraged existing family routines (e.g. dinner) to discuss and co-construct a timeline of the patient's daily activities. One design goal that I have distilled from these studies is to provide individual and private mobile experiences first, and allow families to discuss and choose a means of collaboration that both patients and family members can agree upon.

By eliciting patients' and their families' perspectives toward the use of PHRs (S1–2),

storyboards (S3), diary and media technologies (S5), I have consistently found that families saw value in using personal illness documentation technologies to resolve conflicting interpretations about the patient's health status, distribute the burden of documentation, and provide opportunities for patients to gradually take an active role in managing their care. To design technologies that are in line with these family values, my research suggests that it is important to focus on the goal of understanding distinct roles that patients and family members can serve in documenting experiential data, including symptoms and side effects, and supporting their acclimation to those roles and partnership through the design of technology (S1). My co-design study (S3) in particular showed that patients preferred to capture symptom data along with daily activities while family caregivers collected contextual data such as time and frequency related to the symptom experience. These insights, along with other findings in my work, show promise that warrants further investigation into understanding how families could work together to build a cohesive story of the patient's illness experience while reducing their burden of documentation [153].

9.2 Implications for Clinical Practice

With the proliferation of mobile health data, and PGHD, concerns about the potential burden that such information will place on clinicians' line of work are inevitable. Incorporating patients' preferences to express their illness experiences such as through media data creates additional responsibilities for clinical caregivers who already need to review traditional measures of patient responses to treatment regimens such as the Review of Systems (RoS)—a perfunctory list of questions that clinicians use to elicit medical history and uncover dysfunction and disease. Moreover, concerns over data-related liability can further increase clinicians' perceived burden since mHealth technology enables the collection of granular data about patients' ongoing health status.

There is merit in allowing patients to use both standardized measures and narrative depiction of their health status [205]. For example, there is evidence that patients who

self-reported their pain through narratives showed reduced pain levels and higher well-being scores than those who used traditional measures only [206]. Media data can serve as supporting evidence to substantiate patients' stories. In practice, however, patients are not given ample time to tell their stories. One study reported that, on average, doctors only spent 11 seconds to listen to their patients before they can interrupt them [207].

My research reveals strategies to reduce clinicians' burden on many fronts. S4 revealed opportunities to reduce clinicians' review burden by leveraging existing practices in the clinic, such as distributing review tasks among members (e.g., nursing staff) of the care team, and specifying algorithms for triaging concerning data based on symptom attributes such as frequency, intensity, and interference with daily activities. By designing effective tools to filter and navigate these attributes, and varying the representation of patient-reported data, we can help clinicians manage their attention to focus on important signs of illness. For instance, tools can gradually and dynamically reveal expressive representations of patient data (from numeric ratings, text descriptions, and to media data) upon escalating the severity of illness responses to a higher priority status. Another strategy is to align the output of mobile health data with existing data collection instruments in the clinic. For example, one participant in the pilot deployment study (PS) complained about the redundancies that exist between the daily question and response items in CO-OP and RoS. Preliminary results of this study suggest that aligning the standard RoS entries that the families are required to complete in the clinic with daily assessments in mHealth applications could improve their satisfaction in care by reducing waiting time.

9.3 Future Work

My dissertation highlights promising areas for future work to explore opportunities to design intelligent collaborative health systems. I am excited to explore four areas in which my research can inform the design of such systems.

9.3.1 Impact of Narrative Technologies on Care Quality

The intersection between narratives and technology is a fascinating area to pursue in future research. Through the framing of narratives, I have articulated a design space that includes the expected role of patients and family caregivers as well as technology to drive patient participation in their care. However, more research is needed to understand whether technologies designed to support patient narratives can improve their overall experience with care. Multiple long term deployment studies will be required to evaluate the longitudinal effects of narrative-based technologies on patient engagement, satisfaction, self-efficacy, and health outcomes. In parallel, we need to understand how to design effective ecological momentary assessment (EMA) protocols for mHealth technology deployment studies that not only serves the purpose of collecting patient data but also provide value that is beneficial to them.

Future research will also look at how to improve patients' health literacy in these long term studies. Currently, young patients experience problems discerning one symptomatic experience from another. One study of pediatric oncology patient's descriptions of fatigue reported that while children solely focused on physical sensations, adolescent patients alternated or sometimes merged physical and mental tiredness [208]. Another study by Olver et al. found that many patients receiving chemotherapy used the term 'nausea' to describe multiple symptoms related to their illness experience [209]. My research findings point to opportunities to improve patients' functional health literacy levels when they are provided with visual representations and media technologies that can support increased awareness as well as discernment of vague physical and emotional illness experiences.

My research thus far has focused on adolescent patients with cancer and lupus diagnoses undergoing routine therapy in the Atlanta metropolitan area. While this research offers insights that can be transferable to similar adolescent patient groups suffering from complex chronic conditions (see Chapter 2 for detailed description), it will be important to understand the extent to which findings from this dissertation can be generalized across

different regions, diagnoses and age groups. For instance, the challenges that adolescents experienced can resonate with non-native English-speaking patients who lack the necessary comprehension and communication skills to recognize and articulate their feelings. Moreover, future research can benefit from understanding how to support shared health management in other patient-caregiver relationships such as senior patients and adult child caregivers.

9.3.2 Narratives and Supportive Care

One of the most important implications for my research is discovering the potential role that technology can play and offer in service of supportive care, which describes the provision of services from professional partners in care (e.g., psychologists, nutritionists, and therapists) to meet various bio-psycho-social needs of patients during their diagnostic, treatment, and follow-up phases [24]. A major shortcoming of our current health system is an inability to streamline supportive care. For instance, patients' signs of illness are monitored prior to each encounter, yet clinicians focus on the type of illness and specific reason for which their patients are being seen. Future research can bring the premise of supportive care to other clinical contexts such as chronic kidney disease that lack the resources of a large clinical center.

Designing for story-building, by including flexible ways to capture and elicit patients' illness experiences, has implications for connecting patients to relevant supportive care services at the appropriate time and context in the patient's care processes. Through conversations with adolescent patients in S3, I discovered the potential use of voice notes to seek counseling support from resident psychologists. S5 showed the extent to which adolescent patients can express subjective experiences that are difficult to articulate in their own words. These findings point to opportunities for discovering new scenarios of technology use in supportive care. For instance, patients can record a video of themselves experiencing difficulty walking, to seek support from physical therapists [210], or interact

with art therapists by submitting sketches that express their emotional experience [211].

9.3.3 Family-Centered Collaborative Illness Management

Findings from my research emphasize the need to provide individual and private mobile experiences first, and allow families to choose their own model for sharing observations of the patient's health data. However, private and individual mobile health experiences may not always be guaranteed for adolescents. Smart phone addiction has become a prevalent problem and center of tension among families with an adolescent child, often leading to strict parental regulation over adolescents' mobile device use [212]. For example, 54% of adolescents in the US reported that they spend too much time on their cellphones, and two-thirds of parents expressed concern over their child's screen time [213].

In addition, more research is needed to understand the various ways in which families can reach consensus on data sharing models. In a national study of adolescent portal privacy policies, Sharko et al. found that hospitals relied on the patient's age to determine whether they should have access to their own account (e.g., 12 y.o.) and when their parental caregiver(s) should have restricted access to their child's account (e.g., 18 y.o.) [181]. However, these policies were not successful in preventing some parents from taking over adolescents' accounts to view their medical data. Data sharing models among family members may vary widely depending on the type of family structure (e.g., nuclear, single-parent, step family, etc.). Within each type, families can exhibit varying degrees of family dynamics, which can be influenced by different levels of socioeconomic status as well as ethnic and cultural backgrounds.

Future research will also look at how mobile technologies can complement emerging technologies that have been designed for families and to be used in the home setting. Conversational AI assistants, for example, are gradually taking its place in peoples' homes and becoming a center-piece for families to connect with each other, and there is now growing

interest[1] in its potential to support patient care and illness management.

My research points to future research opportunities to utilize conversational AI technologies for everyday family-centered health management. There is merit in exploring the intersection of mobile (personal) and home-based (family-oriented) experiences as they can offer complementary benefits that meet patients' privacy needs as well as distribute the burden of illness documentation among family members. For example, patients can log private and sensitizing illness experiences on their mobile phones while families can collaboratively build and share patient and family activity routines by engaging with conversational agents.

9.3.4 'In-the-Wild' Design Methods

Another goal for future research is to create and evaluate novel processes for capturing patients' and clinicians' perspectives toward AI-powered technologies in the wild. As a useful starting point, I want to expand on my co-design work to continue developing innovative methods that enable researchers to engage multiple intended users in in-situ design work. However, structuring design activities around AI systems can be challenging: its decisions are often not transparent or explainable to users. How can we understand in advance how people will react to such black box systems, and in which contexts? By advancing in-the-wild methods, we can begin to capture nuanced human-centered perspectives toward the envisioned use of AI in multiple scenarios (along with traditional notions of personal data) to inform usability, ethical, and privacy considerations in designing intelligent and personalized health systems.

[1] Amazon released a HIPAA-compliant platform to house new applications (i.e., Alexa Skills) that can assist patients in their home, hospital rooms, and senior residences.

CHAPTER 10

CONCLUSION AND RESEARCH CONTRIBUTIONS

Pediatric patients face many challenges to participate in their care during complex chronic treatment. In order for computing to support this audience, it must enable pediatric patients to express various physical, psychological, informational, social, and emotional health needs to the care team so they can access relevant health resources when most needed. This communication is challenging because patients, caregivers and clinicians have unmatched experiences, conceptions and linguistic representations of indicators of health. Most importantly, patients lack the means to capture and represent their felt illness experience. My dissertation demonstrates how computing can address these challenges by advancing collaborative approaches for managing personal health data. In particular, I focused on chronically-ill adolescent patients and their family caregivers as an extended case study.

I and my colleagues have investigated how to design a mobile health experience to support adolescent patients' day to day health management with their family caregivers. Through iterative design and deployment of a prototype mobile health application, my research found that we can engage these patients in their own care by providing age-appropriate, relatable, and personalizable representations of health data upon which they can build, to articulate their health status. We can promote patients' gradually-evolving partnerships with family caregivers by providing individual mobile health experiences that allow for both personal use and collaborative reconciliation of illness observations.

Table 10.1: Summary of Research Contributions. S(n)=Study Number

Research Questions	**S(n)**	**Contributions**
What challenges and opportunities shape the design space of patient engagement in care processes for adolescents and family caregivers?	S1	Advanced state of knowledge of patient participation in the clinical setting by identifying their challenges and provided a characterization of the design space (**empirical**).
	S2	Conducted first study and advanced knowledge regarding how a pediatric PHR system influences adolescents' and parents' perspectives, preferences and attitudes about their engagement in care (**empirical**).
How can we elicit information about patient experiences to create illness representations that are meaningful to them and their family members?	S3	Advanced state of knowledge and design insights for ways in which technology can support elicitation of patients' illness narratives (**empirical**). Advanced methods for designing with young patients by adapting a storyboard-based co-design technique (**methodological**). Created design research artifacts (co-design toolkit) for public dissemination to practitioners (**artifact**).
	S4	Advanced state of knowledge regarding clinicians' perspectives toward the use of PGHD in their practice by exploring appropriate techniques for presenting visually-driven representations of PGHD, identifying use cases for incorporating PGHD, and outlining design insights for each (**empirical**).
How can we design computing technology to engage adolescents and their family members in everyday health management?	S5	Established guidelines for designing technologies to support patients' and parents' collaborative documentation for illness management (**empirical**). Advanced methods for in-situ design work with adolescents through mixed application of diary-based tracking and medium probes (**methodological**). Created diary probe (e.g., diary, stickers) for public dissemination (**artifact**).
	PS	Created vector renderings of vODLs, functional mHealth application (CO-OP), robust mobile-based EMA system, and protocol for conducting a long term mobile EMA study (**artifact**).

10.1 Research Contributions

In 2016, Wobbrock and Kientz provided a characterization of seven research contribution types in HCI [214], encompassing theoretical, empirical, methodological, artifact, survey, dataset, and opinion contributions. Based on this characterization, my dissertation has primarily focused on, and produced, empirical, methodological and artifact contributions. In particular, I have provided an empirical understanding of chronically ill adolescents' engagement and participation in care processes, advanced methods for designing for and with vulnerable adolescent patients and their caregivers, and created an innovative mobile health system that accommodates patient and caregiver contributions of their observations in daily life. Below, I use Wobbrock and Kientz's framework to organize my discussion of primary HCI contributions, and elaborate on relevant and complementary research contributions.

10.1.1 Empirical Contributions

Empirical contributions in HCI provide new knowledge through findings based on observation and data gathering [214]. Interview, survey and diary studies are among many different sources that are considered an empirical contribution. In my work, empirical analyses are based on quantitative and qualitative assessments of patient and parent engagement during data collection as well as participation in co-design activities. I describe key lessons and implications that emerge from the empirical contribution of my research.

Defining a Design Space for Patient Participation in Care

In Study 1, I advanced the state of knowledge of current ways in which patients participate in the clinical setting by 1) identifying existing barriers and the delicate privacy needs of adolescents, and 2) setting a research agenda for technology to support patient-parent partnership in managing complex chronic illnesses. I was able to get at participants' candid perspectives through independent interviews that ensured both adolescents and parents that

their responses would be confidential. These independently collected perspectives provided enormous value for my research, since they helped me navigate and define the complex design space for adolescents' health management in pediatric care processes.

Subsequently, in Study 2, I conducted the first study and advanced knowledge regarding the role that a pediatric PHR system could play in influencing adolescents' and parents' perspectives, preferences and attitudes about their engagement in care. Specifically, I learned that the PHR system influenced 1) patients' perceived ability to make sense of their illness, 2) preferences for communicating about their health, and 3) patient and parents' perceived value of a PHR system in their care. For example, I found that patients and parents both valued MyChart, but had different views about the role of the PHR for care communication and management, and different attitudes about its impact on the patient's ability to manage care. Specific motivations for using MyChart included patient–parent coordination of care activities, communication around hospital encounters, and support for transitioning to adult care.

Characterization of Patient-Defined Patient-Generated Health Data

In Study 3, I advanced the state of knowledge and design insights for ways in which technology can support the capture and elicitation of patients' illness narratives. In particular, I provided a characterization of patient-generated health data (PGHD) from the perspective of patients. A key aspect of this characterization is in recognizing the importance of supporting adolescents to express their subjective illness experiences through flexible means that include the use of media tools. The inclusion of adolescents' preferences for expressing their illness, however, brings new considerations to clinical practice, such as understanding the potential impact of using rich data types (e.g, photo, video, etc.) in reviewing and communicating about the patients' health status.

In Study 4, I thus led an investigation of clinicians' perspectives toward the use of flexible representations of PGHD in their practice. In this work, I contributed, 1) an assessment

of the pros and cons of presenting patient-defined PGHD that emphasize the sequential narrative of illness events vs. summative narrative of specific relationships between symptoms and activities, 2) identification of clinicians' preferred use cases for integrating patient-defined PGHD in their work, and 3) design insights for technology to support multiple use cases of integrating PGHD into clinicians' practice.

Design Guidelines for Creating Pediatric Mobile Health Experiences

Informed by Studies 1 through 5, I created a set of seven design guidelines and design goals specific to the context of my research. These guidelines and specific design goals informed the design of a mHealth technology for family-centered health management in the context of cancer and lupus treatment, and they have the potential to inform the creation of technologies for dependent, chronically ill patients whose care relies on the immediate network of family caregivers.

Expansion of Narrative Features

My reflection of lessons learned from these studies, through the lens of narrative medicine, culminated in a detailed characterization (see Table 9.1 in Chapter 9) and expanded interpretation of narrative features that are deemed important to establish meaningful patient-clinician engagements. This characterization includes the potential roles that patient families and technology can fulfill (in addition to those of clinicians) to support patients' participation in care throughout documentation and communication of their illness narratives.

10.1.2 Methodological Contributions

Methodological research contributions create new knowledge that informs how we carry out our work [214]. Example methodological contributions include application, innovation, and adaptation of methods as well as creation of new measures and new instruments. In my work, I have successfully adapted and applied collaborative design methods to incorporate

the unique perspectives of adolescent patients' along with those of their parents and clinical caregivers into the design of collaborative mobile health experiences. I also contributed innovative applications of diary tracking and media probes to engage patient families in documenting their observations of daily living.

Storyboard-based Scaffolding Technique for Co-designing with Pediatric Patients

An advantage of co-design is that it directly involves the intended users of an envisioned technology in the design process to ensure their perspectives are included in the final design artifact. As such, I have adapted storyboard-based co-design techniques to address the limitations of conducting design research with ill adolescent populations. These limitations included the lack of means to elicit adolescents' recall of specific illness experiences, in order to support their articulation of first-person illness narratives during design studies.

Storyboard-based co-design methods that employ scaffolding techniques such as Comicboarding [41] offer huge benefits for young study participants who lack the means to recall and articulate their everyday experiences living with the illness. Contrary to other storyboard scaffolding approaches that start with a few pre-selected image panels to help participants generate ideas, I chose to scaffold the storytelling process from the end by adding the visual illustrations corresponding to each scenario, in the last panel of the storyboard. This way, I was able to draw out illness-related experiences and preferences regarding the imagined use of the technology for multiple scenarios (e.g., remote, in-person, etc.) of communication. Providing this scaffolding for the storytelling process focused on co-designing the beginning and intermittent processes, and allowed enough flexibility to ideate in-between and within Visual ODLs (S3) leading up to the resulting scenario of use.

Combining Diary Tracking with Media Probes

Study 5 illustrated the merit of exploring the intersection between quantitative, repetitive, and predefined tracking (i.e., diary), and exploratory probes-based approaches. I observed

that using both paper diaries and media probes helped patients develop and articulate their personal illness narrative around objective data, in ways that support their autonomy in expression. My research suggests that tools for collaborative documentation work best when offering both paper and digital approaches, as paper affords flexible documentation and review while digital media allows patients to engage in momentary reflections of their lived experiences.

10.1.3 Artifact Contributions

Artifact contributions arise from generative design-driven activities and are evaluated based on how well the designs negotiate trade-offs as well as hold competing priorities in balance [214]. In my work, I created design artifacts called Visual Observations of Daily Living (vODLs) in order to elicit adolescents' experience.

Visual Observations of Daily Living

Over the course of my dissertation research, I designed and iteratively refined visual representations (vODLs) of the patients' daily illness experience. The vODL design artifacts served two roles in my research. First, their inclusion in generative design studies (S3 and S5) helped me arrive at the needed empirical knowledge to guide the design of an mHealth technology artifact. The initial set of 72 sketches emerged from a co-design study (S3), which I then expanded to use in a subsequent diary study (S5). Secondly, a final version of the vODL set (representing 32 activities, 12 emotional-, and 24 physical experiences) comprise the design of a larger technology artifact, also known as CO-OP. I made the vODL artifacts available through the hx.gatech.edu website and distributed them via a creative commons license.

CO-OP mHealth System

All of my design work culminated in a fully functional mHealth application (CO-OP) along with a research protocol that guides large scale system deployment. The application integrates patients' and families' self-reported observations with passively collected data to generate rich perspectives on the patient's illness experiences, including captured media data and collateral information about when and where side effects are occurring. The current version of the application is available on the Google Play store and I plan to make the app publicly available upon completion of the mEMA study.

Appendices

APPENDIX A

INSTRUMENTS

Date: _____ Participant ID: _____

Communication efficacy scale

Rate your degree of confidence by recording a number from 1 to 5 using the scale given below. 1. I'm not at all confident 2. I am a little confident 3. I am somewhat confident 4. I am quite confident 5. I am very confident					
I can ask my doctor questions about my health	1	2	3	4	5
My doctor can understand what I mean when I ask him or her a question about my health	1	2	3	4	5
I can describe a health problem that I have to my doctor	1	2	3	4	5
My doctor can understand me when I answer a question he or she asks	1	2	3	4	5
I can understand the answers my doctor gives to my questions	1	2	3	4	5

Figure A.1: Communication Efficacy Scale (CES).

Date: _____ Participant ID: _____

Health Literacy Assessment Scale for Adolescents (HAS-A)

Response Items: *Never* (0), *Rarely* (1), *Sometimes* (2), *Often* (3), *Always* (4)

Question Items	**Circle one**
1. How often is it easy for you to ask your doctor questions about your health?	0 1 2 3 4
2. How often does your doctor understand what you mean when you ask him or her a question about your health?	0 1 2 3 4
3. How often can you easily describe a health problem you have to your doctor?	0 1 2 3 4
4. How often does your doctor seem to understand you when you answer a question he or she asks?	0 1 2 3 4
5. How often do you understand the answers your doctor gives to your questions? (understand)	0 1 2 3 4
6. How often do you feel confused because you find different information about the same health topic? (process)	0 1 2 3 4
7.How often do you feel confused when you doctor tells you about taking a medicine?	0 1 2 3 4
8. How often do you feel confused when your doctor tells you about possible side effects from a medicine or treatment?	0 1 2 3 4
9. How often do you feel confused when your doctor tells you about test results, like results of an X-ray?	0 1 2 3 4
10. How often do you feel confused when reading instructions for medicine?	0 1 2 3 4
11. How often do you have problems learning about an illness or health topic because of difficulty understanding the written information you get?	0 1 2 3 4
12. How often do you think the forms you complete at your doctor's office are confusing?	0 1 2 3 4
13. How often do you feel confused by health information that has a lot of numbers and statistics?	0 1 2 3 4
14. When you talk to people other than your doctor about health issues, how often do you feel confused by what they tell you?	0 1 2 3 4
15. When reading brochures or hand-outs about health issues, how often do you need someone to help you read them?	0 1 2 3 4

Figure A.2: Health Literacy Assessment Scale for Adolescents (HAS-A).

Date: _____ Participant ID: _____

Collaborative Parent Involvement Scale (patient)

I have a parent who…	Almost Never	Some times	Often	Almost Always	Always
1. Helps me plan my illness care to fit my schedule.	1	2	3	4	5
2. Knows when I need a little extra help with my illness.	1	2	3	4	5
3. Helps me figure out how to change my medication or eating to fit my physical activity.	1	2	3	4	5
4. Helps me out when I am too tired or stressed to take care of my illness on my own.	1	2	3	4	5
5. Knows what things are hard for me in taking care of my illness.	1	2	3	4	5
6. Helps me learn how to take care of troubles I have with my illness.	1	2	3	4	5
7. Knows when to let me do more to take care of myself and my illness.	1	2	3	4	5
8. Helps me plan how to spend time with my friends and still take good care of my illness.	1	2	3	4	5
9. Talks with me about how to adjust (change) my medication, eating, and physical activity.	1	2	3	4	5
10. Helps me with my illness when I need it.	1	2	3	4	5
11. Helps me take care of any problems I am having at school with taking care of my illness.	1	2	3	4	5
12. Knows how I am taking care of my illness when I am with friends.	1	2	3	4	5

Figure A.3: Collaborative Parent Involvement Scale (patient).

Date: _____ Participant ID: _____

Collaborative Parent Involvement Scale (parent)

I am a parent who…	Almost Never	Some times	Often	Almost Always	Always
1. Helps plan my child's illness care to fit their schedule.	1	2	3	4	5
2. Knows when my child needs a little extra help with their illness.	1	2	3	4	5
3. Helps figure out how to change my child's medication or eating to fit their physical activity.	1	2	3	4	5
4. Helps my child out when they are too tired or stressed to take care of the illness on their own.	1	2	3	4	5
5. Knows what things are hard for my child in taking care of their illness.	1	2	3	4	5
6. Helps my child learn how to take care of troubles my child has with my illness.	1	2	3	4	5
7. Knows when to let my child do more to take care of themself and the illness.	1	2	3	4	5
8. Helps my child plan how to spend time with their friends and still take good care of their illness.	1	2	3	4	5
9. Talks with my child about how to adjust (change) their medication, eating, and physical activity.	1	2	3	4	5
10. Helps my child with their illness when they need it.	1	2	3	4	5
11. Helps my child take care of any problems they are having at school with taking care of their illness.	1	2	3	4	5
12. Knows how they are taking care of their illness when they are with friends.	1	2	3	4	5

Figure A.4: Collaborative Parent Involvement Scale (parent).

Date: _____ Participant ID: _____

CO-OP Exit Evaluation Survey

Question Items (Strongly Disagree = 1, Agree = 2, Disagree = 3, Strongly Agree = 4)	Response			
1. I found CO-OP easy to use	1	2	3	4
2. I found CO-OP to be useful	1	2	3	4
3. Questions were easy to understand	1	2	3	4
4. CO-OP could make it easier for me to remember symptoms at my clinic visits	1	2	3	4
5. CO-OP could improve discussions with my doctor/nurse	1	2	3	4
6. CO-OP could improve my communication with my doctor/nurse	1	2	3	4
7. CO-OP made me feel more in control of my own care	1	2	3	4
8. CO-OP could improve the quality of my care	1	2	3	4
9. I would like to continue using CO-OP	1	2	3	4
10. I would recommend CO-OP to other patients	1	2	3	4

*Question Items Adapted from “Basch E, Artz D, Dulko D, Scher K, Sabbatini P, Hensley M, Mitra N, Speakman J, McCabe M, Schrag D. Patient online self-reporting of toxicity symptoms during chemotherapy. Journal of clinIcal oncology. 2005 May 20;23(15):3552-61.”

Figure A.5: CO-OP Exit Evaluation Survey.

APPENDIX B

FIGURES

Categories	Subcategories	*ICD-9* Codes
Neuromuscular	Brain and spinal cord malformations	740.0–742.9
	Mental retardation	318.0–318.2
	Central nervous system degeneration and disease	330.0–330.9, 334.0–334.2, 335.0–335.9
	Infantile cerebral palsy	343.0–343.9
	Muscular dystrophies and myopathies	359.0–359.3
Cardiovascular	Heart and great vessel malformations	745.0–747.4
	Cardiomyopathies	425.0–425.4, 429.1
	Conduction disorders	426.0–427.4
	Dysrhythmias	427.6–427.9
Respiratory	Respiratory malformations	748.0–748.9
	Chronic respiratory disease	770.7
	Cystic fibrosis	277.0
Renal	Congenital anomalies	753.0–753.9
	Chronic renal failure	585
Gastrointestinal	Congenital anomalies	750.3, 751.1–751.3, 751.6–751.9
	Chronic liver disease and cirrhosis	571.4–571.9
	Inflammatory bowel disease	555.0–556.9
Hematologic or immunologic	Sickle cell disease	282.5–282.6
	Hereditary anemias	282.0–282.4
	Hereditary immunodeficiency	279.00–279.9, 288.1–288.2, 446.1
	Acquired immunodeficiency	0420–0421
Metabolic	Amino acid metabolism	270.0–270.9
	Carbohydrate metabolism	271.0–271.9
	Lipid metabolism	272.0–272.9
	Storage disorders	277.3, 277.5
	Other metabolic disorders	275.0–275.3, 277.2, 277.4, 277.6, 277.8–277.9
Other congenital or genetic defect	Chromosomal anomalies	758.0–758.9
	Bone and joint anomalies	259.4, 737.3, 756.0–756.5
	Diaphragm and abdominal wall	553.3, 756.6–756.7
	Other congenital anomalies	759.7–759.9
Malignancy	Malignant neoplasms	140.0–208.9, 235.0–239.9

Figure B.1: Categories of CCCs and Corresponding ICD-9 codes (table reproduced from Feudtner et al. [7]).

Table One. Defining needs of individuals living with cancer: Categories of needs and examples			
Definition of Need Categories	Specific Examples of Supportive Care Symptoms and Needs in Cancer		
Physical Needs for physical comfort and freedom from pain, optimum nutrition, ability to carry out one's usual day-to-day functions (i.e., activities of daily living)	• pain • weakness • fatigue • anorexia • nausea • vomiting • mobility • lymphedema	• incontinence • thirst • cough • shortness of breath • spitting up blood • loss of appetite • hair loss	• impotence • changes in bowel habits • difficulties with diet/fluid intake • difficulties with sleeping • weight changes • menopause • difficulties swallowing/speaking • fertility
Informational Needs for information to reduce confusion, anxiety and fear; to inform the person's or family's decision-making; and to assist in skill acquisition	• cancer treatment and side effects procedures/test results • how to handle or manage side effects • care processes	• communication with caregivers • orientation to treatment facility • educational resources (appropriate) • help with decision-making	
Emotional Needs for a sense of comfort, belonging, understanding and reassurance in times of stress and upset	• fear • distress • anxiety • depression • anger	• guilt • grief • abandonment • hopelessness	• to talk with a peer • powerlessness • shame/self-blame • isolation
Psychological Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem	• changes in lifestyle • sexual problems • diminished cognitive ability • loss	• loss of personal control • major depression • anxiety disorders • self-image problems • body image changes • fear of recurrence	
Social Needs related to family relationships, community acceptance and involvement in relationships	• changes in roles • difficulty dealing with the responses of family members/children • social relationships • interpersonal communication • telling other people		
Spiritual Needs related to the meaning and purpose in life to practice religious beliefs	• search for meaning • existential despair	• examine personal values, priorities • spiritual crisis/resolution • feelings of hopelessness	
Practical Needs for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person (e.g., homemaking services, financial assistance)	• daily home help • shopping • transportation • child care • prosthesis • travel to and from treatment appointments	• assistance in activities of daily living • provision of family relief • stresses involving family, children, parents, etc. • financial issues • legal issues • employment issues/school issues • menu planning/food preparation	

Figure B.2: Supportive Care Needs (table reproduced from Fitch et al. [23]).

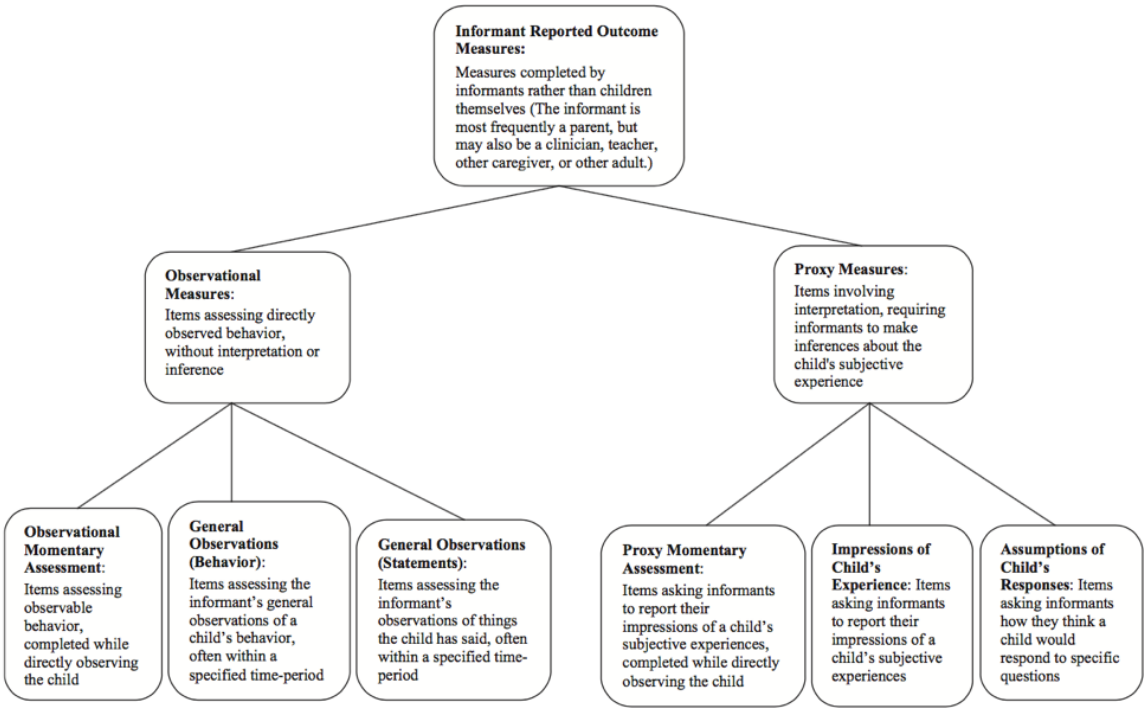

Figure B.3: Types of Caregiver-Reported Outcome Measures for Pediatric Assessment. Figure adapted from [108].

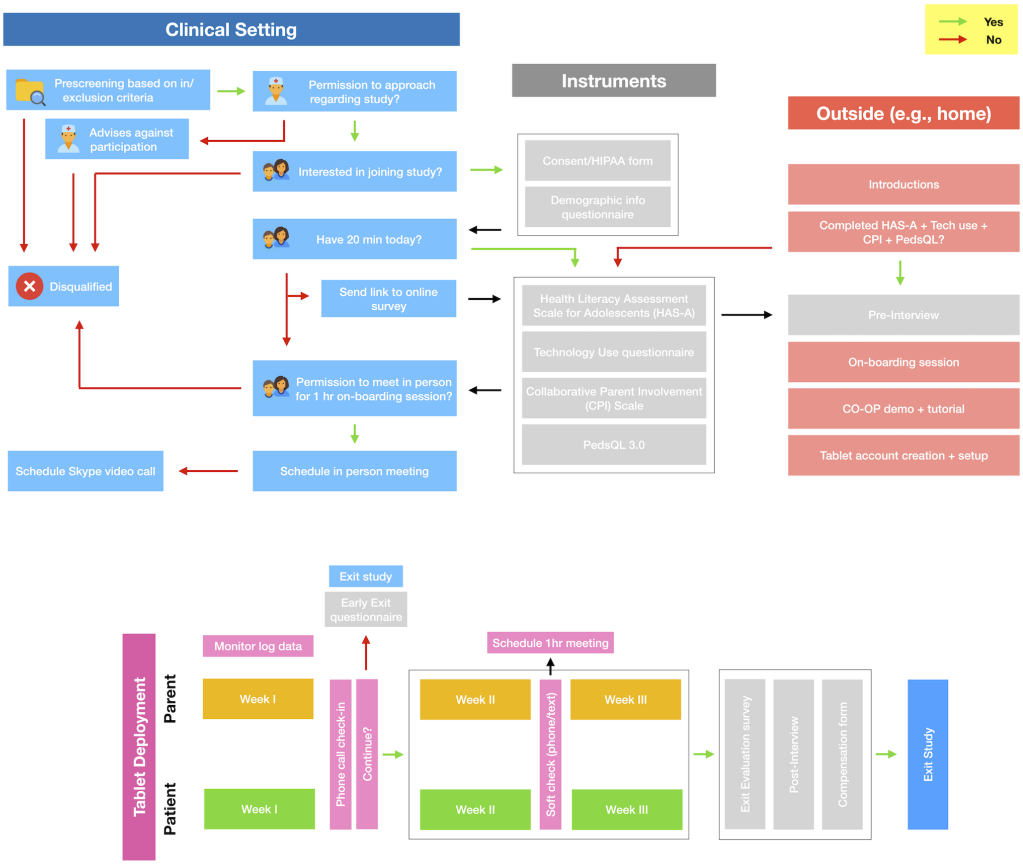

Figure B.4: CO-OP Pilot Study Protocol Flowchart. This flowchart visualizes different steps involved in the pilot study protocol.

REFERENCES

[1] K. Tates and L. Meeuwesen, "Doctor–parent–child communication. A (re) view of the literature," *Social science & medicine*, vol. 52, no. 6, pp. 839–851, 2001.

[2] S. Williams, J. Weinman, and J. Dale, "Doctor-patient communication and patient satisfaction: a review," *Family Practice*, vol. 15, no. 5, pp. 480–492, 1998.

[3] M. R. DiMatteo, "The role of effective communication with children and their families in fostering adherence to pediatric regimens," *Patient education and counseling*, vol. 55, no. 3, pp. 339–344, 2004.

[4] *The Health Information Technology for Economic and Clinical Health (HITECH) Act from ARRA Act of 2009*.

[5] C. F. Snyder, R. E. Jensen, J. B. Segal, and A. W. Wu, "Patient-reported outcomes (PROs): putting the patient perspective in patient-centered outcomes research.," *Medical care*, vol. 51, no. 8 Suppl 3, pp. 73–9, Aug. 2013.

[6] H. Hutchinson, H. Hansen, N. Roussel, B. Eiderbäck, W. Mackay, B. Westerlund, B. B. Bederson, A. Druin, C. Plaisant, M. Beaudouin-Lafon, S. Conversy, and H. Evans, "Technology Probes: Inspiring Design for and with Families," in *Proceedings of the conference on Human factors in computing systems - CHI '03*, New York, New York, USA: ACM Press, Apr. 2003, p. 17, ISBN: 1581136307.

[7] C. Feudtner, R. M. Hays, G. Haynes, J. R. Geyer, J. M. Neff, and T. D. Koepsell, "Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services," *Pediatrics*, vol. 107, no. 6, e99–e99, 2001.

[8] J. M. Perrin, S. R. Bloom, and S. L. Gortmaker, "The increase of childhood chronic conditions in the United States.," *JAMA*, vol. 297, no. 24, pp. 2755–9, Jun. 2007.

[9] R. L. Siegel, K. D. Miller, and A. Jemal, "Cancer Statistics, 2018," *CA: A Cancer Journal for Clinicians*, vol. 68, no. 1, pp. 7–30, Jan. 2018.

[10] National Cancer Institute, *Surveillance, Epidemiology, and End Results Program*.

[11] *Systemic Lupus Erythematosus (Lupus) in Children and Teens*.

[12] Y. Chen, *Health information use in chronic care cycles*, 2011.

[13] P. G. Corrie, "Cytotoxic Chemotherapy: Clinical Aspects," *Medicine*, vol. 36, no. 1, pp. 24–28, Jan. 2008.

[14] M. L. Jacobs, J. Clawson, and E. D. Mynatt, *My journey compass: a preliminary investigation of a mobile tool for cancer patients*, Toronto, ON, Canada, 2014.

[15] *Chemotherapy to Treat Cancer - National Cancer Institute*.

[16] MedlinePlus, *Methotrexate: MedlinePlus Drug Information*, 2017.

[17] C. M. Reilly, D. W. Bruner, S. A. Mitchell, L. M. Minasian, E. Basch, A. C. Dueck, D. Cella, and B. B. Reeve, "A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment," *Supportive Care in Cancer*, vol. 21, no. 6, pp. 1525–1550, Jun. 2013.

[18] N. Boykoff, M. Moieni, and S. K. Subramanian, "Confronting chemobrain: an in-depth look at survivors' reports of impact on work, social networks, and health care response," *Journal of Cancer Survivorship*, vol. 3, no. 4, pp. 223–232, Dec. 2009.

[19] R. A. Patel, P. Klasnja, A. Hartzler, K. T. Unruh, and W. Pratt, "Probing the benefits of real-time tracking during cancer care," in *AMIA Annual Symposium Proceedings*, vol. 2012, American Medical Informatics Association, 2012, p. 1340.

[20] E. Tsangaris, J. Johnson, R. Taylor, L. Fern, D. Bryant-Lukosius, R. Barr, G. Fraser, and A. Klassen, "Identifying the supportive care needs of adolescent and young adult survivors of cancer: a qualitative analysis and systematic literature review," *Supportive Care in Cancer*, vol. 22, no. 4, pp. 947–959, Apr. 2014.

[21] PDQ Supportive and Palliative Care Editorial Board, *Pediatric Supportive Care (PDQ®): Patient Version*. 2002.

[22] N. E. Adler and A. E. K. Page, *Cancer Care for the Whole Patient:: Meeting Psychosocial Health Needs*. National Academies Press, 2008, ISBN: 0309111072.

[23] M. Fitch, *Canadian oncology nursing journal Revue canadienne de soins infirmiers en oncologie*, 1. Canadian Association of Nurses in Oncology, 1991, vol. 18, pp. 6–14.

[24] R. Sanson-Fisher, A. Girgis, A. Boyes, B. Bonevski, L. Burton, and P. Cook, "The unmet supportive care needs of patients with cancer," *Cancer*, vol. 88, no. 1, pp. 226–237, Jan. 2000.

[25] *Teen Content Creators and Consumers — Pew Research Center*.

[26] Pew Research Center, "Teens, Social Media & Technology 2018 — Pew Research Center," Tech. Rep.

[27] F. Bentley, K. Church, B. Harrison, K. Lyons, and M. Rafalow, "Three Hours a Day: Understanding Current Teen Practices of Smartphone Application Use," *ACM Transactions on Computer-Human Interaction*, Oct. 2015.

[28] T.-J. Yun and R. I. Arriaga, *A text message a day keeps the pulmonologist away*, Paris, France, 2013.

[29] R. Bassett, B. L. Beagan, S. Ristovski-Slijepcevic, and G. E. Chapman, "Tough Teens: The Methodological Challenges of Interviewing Teenagers as Research Participants," *Journal of Adolescent Research*, vol. 23, no. 2, pp. 119–131, Mar. 2008.

[30] E. S. Poole and T. Peyton, "Interaction Design Research with Adolescents," in *Proceedings of the 12th International Conference on Interaction Design and Children - IDC '13*, New York, New York, USA: ACM Press, Jun. 2013, pp. 211–217, ISBN: 9781450319188.

[31] A. Druin and Allison, "Cooperative Inquiry: Developing New Technologies for Children with Children," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ser. CHI '99, New York, NY, USA: ACM, 1999, pp. 592–599, ISBN: 0-201-48559-1.

[32] H. MacLeod, B. Jelen, A. Prabhakar, L. Oehlberg, K. Siek, and K. Connelly, "Asynchronous remote communities (ARC) for researching distributed populations," *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, pp. 1–8, 2016.

[33] S. E. Drew, R. E. Duncan, and S. M. Sawyer, "Visual Storytelling: A Beneficial But Challenging Method for Health Research With Young People," *Qualitative Health Research*, vol. 20, no. 12, pp. 1677–1688, Dec. 2010.

[34] R. W. Strack, C. Magill, and K. McDonagh, "Engaging Youth through Photovoice," *Health Promotion Practice*, vol. 5, no. 1, pp. 49–58, Jan. 2004.

[35] K. Hieftje, L. R. Duncan, and L. E. Fiellin, "Novel Methods to Collect Meaningful Data from Adolescents for the Development of Health Interventions," *Health promotion practice*, vol. 15, no. 5, pp. 714–22, Sep. 2014.

[36] L. S. Liu, J. Huh, T. Neogi, K. Inkpen, and W. Pratt, "Health Vlogger-Viewer Interaction in Chronic Illness Management," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*, New York, New York, USA: ACM Press, 2013, p. 49, ISBN: 9781450318990.

[37] M. Rich, S. Lamola, J. Gordon, and R. Chalfen, "Video Intervention/Prevention Assessment: A Patient-Centered Methodology for Understanding the Adolescent Illness Experience," *Journal of Adolescent Health*, vol. 27, no. 3, pp. 155–165, Sep. 2000.

[38] T. Peyton and E. Poole, *"My Mobile Health, My Mobile Life": methods for designing health interventions with adolescents*, Paris, France, 2013.

[39] M. Rich, S. Lamola, and E. R. Woods, "Effects of creating visual illness narratives on quality of life with asthma: A pilot intervention study," *Journal of Adolescent Health*, vol. 38, no. 6, pp. 748–752, Jun. 2006.

[40] J. A. Fails, M. L. Guha, and A. Druin, "Methods and Techniques for Involving Children in the Design of New Technology for Children," *Foundations and Trends® in Human–Computer Interaction*, vol. 6, no. 2, pp. 85–166, 2012.

[41] N. Moraveji, J. Li, J. Ding, P. O'Kelley, and S. Woolf, "Comicboarding: Using Comics as Proxies for Participatory Design with Children," in *Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '07*, New York, New York, USA: ACM Press, 2007, p. 1371, ISBN: 9781595935939.

[42] A. Hiniker, K. Sobel, and B. Lee, "Co-Designing with Preschoolers Using Fictional Inquiry and Comicboarding," in *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, New York, New York, USA: ACM Press, 2017, pp. 5767–5772, ISBN: 9781450346559.

[43] E. Tulving and D. M. Thomson, "Encoding specificity and retrieval processes in episodic memory.," *Psychological Review*, vol. 80, no. 5, pp. 352–373, 1973.

[44] S. Hodges, L. Williams, E. Berry, S. Izadi, J. Srinivasan, A. Butler, G. Smyth, N. Kapur, and K. Wood, "SenseCam: A Retrospective Memory Aid," in *Proceedings of the 8th International Conference on Ubiquitous Computing*, ser. UbiComp'06, Berlin, Heidelberg: Springer, 2006, pp. 177–193, ISBN: 978-3-540-39634-5.

[45] A. J. Sellen and S. Whittaker, "Beyond total capture," *Communications of the ACM*, vol. 53, no. 5, p. 70, May 2010.

[46] G. Marcu, A. Dey, and S. Kiesler, "Designing for Collaborative Reflection," in *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare*, ICST, 2014, pp. 9–16, ISBN: 978-1-63190-011-2.

[47] D. A. Epstein, A. Ping, J. Fogarty, and S. A. Munson, "A lived informatics model of personal informatics," in *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing - UbiComp '15*, New York, New York, USA: ACM Press, 2015, pp. 731–742, ISBN: 9781450335744.

[48] E. P. Baumer, V. Khovanskaya, M. Matthews, L. Reynolds, V. Schwanda Sosik, and G. Gay, "Reviewing Reflection: On the Use of Reflection in Interactive System Design," in *Proceedings of the 2014 conference on Designing interactive systems - DIS '14*, New York, New York, USA: ACM Press, 2014, pp. 93–102, ISBN: 9781450329026.

[49] W. F. Brewer, "Memory for randomly sampled autobiographical events," in *Remembering reconsidered*, U. Neisser and E. Winograd, Eds., Cambridge: Cambridge University Press, pp. 21–90.

[50] M. M. K. Hong, U. Lakshmi, T. T. A. Olson, and L. Wilcox, "Visual ODLs: Co-Designing Patient-Generated Observations of Daily Living to Support Data-Driven Conversations in Pediatric Care," in *Conference on Human Factors in Computing Systems - Proceedings*, New York, New York, USA: ACM Press, 2018, pp. 1–13, ISBN: 9781450356206.

[51] L. Wheeler and H. T. Reis, "Self-Recording of Everyday Life Events: Origins, Types, and Uses," *Journal of Personality*, vol. 59, no. 3, pp. 339–354, Sep. 1991.

[52] L. Chan, V. D. Swain, C. Kelley, K. de Barbaro, G. D. Abowd, and L. Wilcox, "Students' Experiences with Ecological Momentary Assessment Tools to Report on Emotional Well-being," *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, vol. 2, no. 1, pp. 1–20, Mar. 2018.

[53] S. Intille, C. Haynes, D. Maniar, A. Ponnada, and J. Manjourides, "μEMA: Microinteraction-based ecological momentary assessment (EMA) using a smartwatch," in *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing - UbiComp '16*, New York, New York, USA: ACM Press, 2016, pp. 1124–1128, ISBN: 9781450344616.

[54] D. L. Ashbrook, "Enabling mobile microinteractions," PhD thesis, Jan. 2010.

[55] X. Zhang, L. R. Pina, and J. Fogarty, "Examining Unlock Journaling with Diaries and Reminders for In Situ Self-Report in Health and Wellness," in *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16*, ser. CHI '16, New York, New York, USA: ACM Press, 2016, pp. 5658–5664, ISBN: 9781450333627.

[56] E. K. Choe, N. B. Lee, B. Lee, W. Pratt, J. A. Kientz, E. K. Choe, N. B. Lee, B. Lee, W. Pratt, and J. A. Kientz, "Understanding quantified-selfers' practices in collecting and exploring personal data," in *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14*, New York, New York, USA: ACM Press, 2014, pp. 1143–1152, ISBN: 9781450324731.

[57] E. K. Choe, S. Abdullah, M. Rabbi, E. Thomaz, D. A. Epstein, F. Cordeiro, M. Kay, G. D. Abowd, T. Choudhury, J. Fogarty, B. Lee, M. Matthews, and J. A. Kientz, "Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications," *IEEE Pervasive Computing*, vol. 16, no. 1, pp. 74–84, Jan. 2017.

[58] L Mamykina, E. D. Mynatt, P. R. Davidson, D Greenblatt, and Acm, "MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, New York, New York, USA: ACM Press, Apr. 2008, pp. 477–486, ISBN: 9781605580111.

[59] M. Kay, D. Morris, M. Schraefel, and J. A. Kientz, "There's No Such Thing as Gaining a Pound: Reconsidering the Bathroom Scale User Interface," in *Proceedings of the 2013 ACM international joint conference on Pervasive and ubiquitous computing - UbiComp '13*, New York, New York, USA: ACM Press, 2013, p. 401, ISBN: 9781450317702.

[60] L. Kendall, D. Morris, and D. Tan, "Blood Pressure Beyond the Clinic: Rethinking a Health Metric for Everyone," in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, New York, New York, USA: ACM Press, 2015, pp. 1679–1688, ISBN: 9781450331456.

[61] *Pediatric Care — Children's Healthcare of Atlanta*.

[62] "Hematology/Oncology Fellowship Program," Tech. Rep.

[63] P. Conrad and K. K. Barker, "The social construction of illness: key insights and policy implications.," *Journal of health and social behavior*, vol. 51 Suppl, no. 1_suppl, pp. 67–79, Mar. 2010.

[64] A. Kleinman, "Suffering, Healing and The Human Condition," *Encyclopedia of Human Biology*, 1988.

[65] A. W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics*. University of Chicago Press, 2013.

[66] L. A. DeSalvo, *Writing as a Way of Healing: How Telling Our Stories Transforms Our Lives*. Beacon Press, 2000.

[67] R. Charon, *Narrative Medicine: Honoring the Stories of Illness*. Oxford University Press, 2008.

[68] M. Hojat, D. Z. Louis, F. W. Markham, R. Wender, C. Rabinowitz, and J. S. Gonnella, "Physicians' Empathy and Clinical Outcomes for Diabetic Patients," *Academic Medicine*, vol. 86, no. 3, pp. 359–364, Mar. 2011.

[69] *Medscape Physician Compensation Report 2018*.

[70] J. Adler-Milstein, *Electronic health record time among outpatient physicians: Reflections on the who, what, and why*, Feb. 2020.

[71] L. Squitieri, K. J. Bozic, and A. L. Pusic, "The Role of Patient-Reported Outcome Measures in Value-Based Payment Reform," *Value in Health*, vol. 20, no. 6, pp. 834–836, Jun. 2017.

[72] *Value-Based Care - Health IT Playbook*.

[73] S. Ford, L. Fallowfield, and S. Lewis, "Doctor-patient interactions in oncology," *Social science & medicine*, vol. 42, no. 11, pp. 1511–1519, 1996.

[74] J. H. Hibbard, "Moving toward a more patient-centered health care delivery system," *HEALTH AFFAIRS-MILLWOOD VA THEN BETHESDA MA-*, vol. 23, VAR–133, 2004.

[75] J. H. Hibbard and J. Greene, "What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs," *Health Affairs*, vol. 32, no. 2, pp. 207–214, 2013.

[76] J. H. Hibbard, "Patient activation and the use of information to support informed health decisions," *Patient Education and Counseling*, vol. 100, no. 1, pp. 5–7, Jan. 2017.

[77] J. B. Brown, W. W. Weston, and M. Stewart, "The first component: exploring both the disease and the illness experience," *Patient-centered Medicine. Transforming the Clinical Method*, vol. 2, pp. 3–52, 1995.

[78] D. S. Rosen, "Transition to adult health care for adolescents and young adults with cancer," 1993.

[79] H. Ledford, "Who exactly counts as an adolescent?" *Nature 2018 554:7693*, Feb. 2018.

[80] J. G. Reiss, R. W. Gibson, and L. R. Walker, "Health care transition: youth, family, and provider perspectives," *Pediatrics*, vol. 115, no. 1, pp. 112–120, 2005.

[81] J. A. Kientz, *Understanding parent-pediatrician interactions for the design of health technologies*, 2010.

[82] M. A. McManus, L. R. Pollack, W. C. Cooley, J. W. McAllister, D. Lotstein, B. Strickland, and M. Y. Mann, "Current Status of Transition Preparation Among Youth With Special Needs in the United States," *Pediatrics*, vol. 131, no. 6, 2013.

[83] A. A. o. Pediatrics, A. A. o. F. Physicians, and A. C. o. P.-A. S. o. I. Medicine, "A consensus statement on health care transitions for young adults with special health care needs," *Pediatrics*, vol. 110, no. Supplement 3, pp. 1304–1306, 2002.

[84] R. Bayer, J. Santelli, and R. Klitzman, "New Challenges for Electronic Health Records: Confidentiality and Access to Sensitive Health Information About Parents and Adolescents.," *The Journal of the American Medical Association*, vol. 313, no. 1, pp. 29–30, Jan. 2015.

[85] F. C. Bourgeois, P. L. Taylor, S. J. Emans, D. J. Nigrin, and K. D. Mandl, "Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients.," *Journal of the American Medical Informatics Association : JAMIA*, vol. 15, no. 6, pp. 737–43, Jan. 2008.

[86] J Carlisle, D Shickle, M Cork, and A McDonagh, "Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration.," *Journal of medical ethics*, vol. 32, no. 3, pp. 133–7, Mar. 2006.

[87] C. Ford, A. English, and G. Sigman, "Confidential health care for adolescents: position paper of the Society for Adolescent Medicine," *Journal of Adolescent Health*, vol. 35, no. 2, pp. 160–167, 2004.

[88] T. Park, P. Chira, K. Miller, and L. Nugent, "Living Profiles: an example of user-centered design in developing a teen-oriented personal health record," *Personal and Ubiquitous Computing*, vol. 19, no. 1, pp. 69–77, Jan. 2015.

[89] F. C. Bourgeois, K. D. Mandl, D. Shaw, D. Flemming, and D. J. Nigrin, "Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population.," in *Proceedings of the American Medical Informatics Association Annual Symposium*, 2009, pp. 65–69.

[90] A. Grimes, V. Kantroo, and R. E. Grinter, *Let's play!: mobile health games for adults*, Copenhagen, Denmark, 2010.

[91] S. Consolvo, P. Klasnja, D. W. McDonald, D. Avrahami, J. Froehlich, L. LeGrand, R. Libby, K. Mosher, and J. A. Landay, *Flowers or a robot army?: encouraging awareness & activity with personal, mobile displays*, 2008.

[92] R. De Oliveira, M. Cherubini, and N. Oliver, *MoviPill: improving medication compliance for elders using a mobile persuasive social game*, 2010.

[93] R. I. Arriaga, "Using an ecological systems approach to target technology," *Autism Imaging and Devices*, p. 419, 2017.

[94] J. O. Prochaska, W. F. Velicer, C. C. DiClemente, and J. Fava, "Measuring processes of change: applications to the cessation of smoking," *Journal of consulting and clinical psychology*, vol. 56, no. 4, p. 520, 1988.

[95] M. H. Becker, *The health belief model and personal health behavior*, 4. Slack, 1974, vol. 2.

[96] R. B. Cialdini, "The Science of Persuasion," *Scientific American*, vol. 284, no. 2, p. 76, 2001.

[97] L. Festinger, "A theory of social comparison processes," *Human relations*, vol. 7, no. 2, pp. 117–140, 1954.

[98] A. D. Miller, "Social tools for everyday adolescent health," 2014.

[99] T. Toscos, A. Faber, S. An, and M. P. Gandhi, *Chick clique: persuasive technology to motivate teenage girls to exercise*, 2006.

[100] A. D. Miller and E. D. Mynatt, *StepStream: a school-based pervasive social fitness system for everyday adolescent health*, 2014.

[101] E. S. Poole, A. D. Miller, Y. Xu, E. Eiriksdottir, R. Catrambone, and E. D. Mynatt, *The place for ubiquitous computing in schools: lessons learned from a school-based intervention for youth physical activity*, 2011.

[102] A. Macvean and J. Robertson, *Understanding exergame users' physical activity, motivation and behavior over time*, 2013.

[103] S. M. Sawyer, S. Drew, M. S. Yeo, and M. T. Britto, "Adolescents with a Chronic Condition: Challenges Living, Challenges Treating," *The Lancet*, vol. 369, no. 9571, pp. 1481–1489, 2007.

[104] M. Shapiro, D. Johnston, J. Wald, and D. Mon, "Patient-Generated Health Data White Paper: White Paper Prepared for the Office of the National Coordinator for Health IT by RTI International.," RTI International 3040 Cornwallis Road Research Triangle Park, NC 27709, Tech. Rep., 2012.

[105] P. F. Brennan, S. Downs, and G. Casper, "Project HealthDesign: rethinking the power and potential of personal health records," *Journal of biomedical informatics*, vol. 43, no. 5, S3–S5, 2010.

[106] P. F. Brennan and G. Casper, "Observing health in everyday living: ODLs and the care-between-the-care," *Personal and Ubiquitous Computing*, vol. 19, no. 1, pp. 3–8, Jan. 2015.

[107] P. R. Deshpande, S. Rajan, B. L. Sudeepthi, and C. P. Abdul Nazir, "Patient-Reported Outcomes: A New Era in Clinical Research.," *Perspectives in clinical research*, vol. 2, no. 4, pp. 137–44, Oct. 2011.

[108] U. D. of Health, U. D. o. H. Human Services FDA Center for Drug Evaluation, H. S. F. C. for Biologics Evaluation, U. D. o. H. Research, H. S. F. C. for Devices, and R. Health, "Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance.," Tech. Rep., 2006, p. 79.

[109] J. M. Landgraf, "Practical considerations in the measurement of HRQoL in child/adolescent clinical trials," *Assessing quality of life in clinical trials: methods and practice*, pp. 339–367, 2005.

[110] R. E. Jensen, C. F. Snyder, A. P. Abernethy, E. Basch, A. L. Potosky, A. C. Roberts, D. R. Loeffler, and B. B. Reeve, "Review of Electronic Patient-Reported Outcomes Systems Used in Cancer Clinical Care," *Journal of Oncology Practice*, vol. 10, no. 4, e215–e222, Jul. 2014.

[111] E. Basch, A. M. Deal, M. G. Kris, H. I. Scher, C. A. Hudis, P. Sabbatini, L. Rogak, A. V. Bennett, A. C. Dueck, T. M. Atkinson, J. F. Chou, D. Dulko, L. Sit, A. Barz, P. Novotny, M. Fruscione, J. A. Sloan, and D. Schrag, "Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial," *Journal of Clinical Oncology*, vol. 34, no. 6, Feb. 2016.

[112] J. Chen, L. Ou, and S. J. Hollis, "A Systematic Review of the Impact of Routine Collection of Patient Reported Outcome Measures on Patients, Providers and Health Organisations in an Oncologic Setting," *BMC Health Services Research*, vol. 13, no. 1, p. 211, Dec. 2013.

[113] A. L. Hartzler, J. P. Izard, B. L. Dalkin, S. P. Mikles, and J. L. Gore, "Design and feasibility of integrating personalized PRO dashboards into prostate cancer care," *Journal of the American Medical Informatics Association*, ocv101, 2015.

[114] D. S. Zhukovsky, C. L. Rozmus, R. S. Robert, E. Bruera, R. J. Wells, G. B. Chisholm, J. A. Allo, and M. Z. Cohen, "Symptom Profiles in Children with Advanced Cancer: Patient, Family Caregiver, and Oncologist Ratings," *Cancer*, vol. 121, no. 22, pp. 4080–4087, Nov. 2015.

[115] J. E. Thorn, N. DeLellis, J. P. Chandler, and K. Boyd, "Parent and Child Self-Reports of Dietary Behaviors, Physical Activity, and Screen Time," *The Journal of Pediatrics*, vol. 162, no. 3, pp. 557–561, 2013.

[116] N. C. M. Theunissen, T. G. C. Vogels, H. M. Koopman, G. H. W. Verrips, K. A. H. Zwinderman, S. P. Verloove-Vanhorick, and J. M. Wit, "The proxy problem: child

report versus parent report in health-related quality of life research," *Quality of Life Research*, vol. 7, no. 5, pp. 387–397, 1998.

[117] R. B. Levi and D. Drotar, "Health-Related Quality of Life in Childhood Cancer: Discrepancy in Parent-Child Reports," *International Journal of Cancer*, vol. 83, no. S12, pp. 58–64, Jan. 1999.

[118] C. Miaskowski, E. F. Zimmer, K. M. Barrett, S. L. Dibble, and M. Wallhagen, "Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes," *PAIN*, vol. 72, no. 1, pp. 217–226, 1997.

[119] L. S. Matza, D. L. Patrick, A. W. Riley, J. J. Alexander, L. Rajmil, A. M. Pleil, and M. Bullinger, "Pediatric Patient-Reported Outcome Instruments for Research to Support Medical Product Labeling: Report of the ISPOR PRO Good Research Practices for the Assessment of Children and Adolescents Task Force," *Value in Health*, vol. 16, no. 4, pp. 461–479, 2013.

[120] L. S. Schilling, J. K. Dixon, K. A. Knafl, M. Grey, B. Ives, and M. R. Lynn, "Determining Content Validity of a Self-Report Instrument for Adolescents Using a Heterogeneous Expert Panel," *Nursing Research*, vol. 56, no. 5, pp. 361–366, Sep. 2007.

[121] PROMIS, *Patient-Reported Outcomes Measurement Information System: Dynamic Tools to Measure Health Outcomes from the Patient Perspective*, 2015.

[122] J. W. Varni, M. Seid, and P. S. Kurtin, "PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations," *Medical care*, vol. 39, no. 8, pp. 800–812, 2001.

[123] E. Basch, B. B. Reeve, S. A. Mitchell, S. B. Clauser, L. M. Minasian, A. C. Dueck, T. R. Mendoza, J. Hay, T. M. Atkinson, A. P. Abernethy, D. W. Bruner, C. S. Cleeland, J. A. Sloan, R. Chilukuri, P. Baumgartner, A. Denicoff, D. St. Germain, A. M. O'Mara, A. Chen, J. Kelaghan, A. V. Bennett, L. Sit, L. Rogak, A. Barz, D. B. Paul, and D. Schrag, "Development of the National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)," *JNCI Journal of the National Cancer Institute*, vol. 106, no. 9, dju244–dju244, Sep. 2014.

[124] C. F. Snyder, K. C. Smith, E. T. Bantug, E. E. Tolbert, A. L. Blackford, and M. D. Brundage, "What Do These Scores Mean? Presenting Patient-Reported Outcomes Data to Patients and Clinicians to Improve Interpretability," *Cancer*, Jan. 2017.

[125] A. M. Barbarin, P. Klasnja, and T. C. Veinot, "Good or Bad, Ups and Downs, and Getting Better: Use of Personal Health Data for Temporal Reflection in Chronic

Illness," *International Journal of Medical Informatics*, vol. 94, no. 0, pp. 237–245, Jun. 2016.

[126] M. K. Hong, L. Wilcox, D. Machado, T. A. Olson, and S. F. Simoneaux, "Care Partnerships: Toward Technology to Support Teens' Participation in Their Health Care," in *Proceedings of the 34th annual ACM Conference on Human Factors in Computing Systems*, San Jose, CA, 2016, ISBN: 9781450333627.

[127] M. M. K. Hong, L. Wilcox, C. Feustel, K. Wasilewski-Masker, T. A. T. Olson, S. S. F. Simoneaux, K. Wasileski-Masker, T. A. T. Olson, S. S. F. Simoneaux, K. Wasilewski-Masker, T. A. T. Olson, and S. S. F. Simoneaux, "Adolescent and Caregiver use of a Tethered Personal Health Record System," in *AMIA Annual Symposium Proceedings*, vol. 2016, Chicago: American Medical Informatics Association, 2016.

[128] M. Zwaanswijk, K. Tates, S. van Dulmen, P. M. Hoogerbrugge, W. A. Kamps, A. Beishuizen, and J. M. Bensing, "Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences," *Psycho-Oncology*, vol. 20, no. 3, pp. 269–277, 2011.

[129] J. M. Najman, G. M. Williams, J. Nikles, S. Spence, W. Bor, M. O'Callaghan, R. Le Brocque, M. J. Andersen, and G. J. Shuttlewood, "Bias influencing maternal reports of child behaviour and emotional state," *Social psychiatry and psychiatric epidemiology*, vol. 36, no. 4, pp. 186–194, 2001.

[130] C. Eiser and R. Morse, "Can parents rate their child's health-related quality of life? Results of a systematic review," *Quality of Life Research*, vol. 10, no. 4, pp. 347–357, 2001.

[131] J. Barlow, C. Wright, J. Sheasby, A. Turner, and J. Hainsworth, "Self-management approaches for people with chronic conditions: a review," *Patient education and counseling*, vol. 48, no. 2, pp. 177–187, 2002.

[132] J. M. Corbin and A. Strauss, *Unending work and care: Managing chronic illness at home*. Jossey-Bass, 1988, ISBN: 1555420826.

[133] K. R. Lorig and H. R. Holman, "Self-management education: history, definition, outcomes, and mechanisms," *Annals of behavioral medicine*, vol. 26, no. 1, pp. 1–7, 2003.

[134] D. Schulman-Green, S. Jaser, F. Martin, A. Alonzo, M. Grey, R. McCorkle, N. S. Redeker, N. Reynolds, and R. Whittemore, "Processes of Self-Management in Chronic Illness," *Journal of Nursing Scholarship*, vol. 44, no. 2, pp. 136–144, 2012.

[135] J. Fereday and E. Muir-Cochrane, "Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development," *International journal of qualitative methods*, vol. 5, no. 1, pp. 80–92, 2008.

[136] T. Ketterer, D. W. West, V. P. Sanders, J. Hossain, M. C. Kondo, and I. Sharif, "Correlates of patient portal enrollment and activation in primary care pediatrics.," *Academic pediatrics*, vol. 13, no. 3, pp. 264–71, Jan. 2013.

[137] D. A. Bergman, N. L. Brown, and S. Wilson, "Teen use of a patient portal: a qualitative study of parent and teen attitudes," *Perspect Health Inf Manag*, vol. 5, p. 13, Jan. 2008.

[138] K. D. Mandl, W. W. Simons, W. C. R. Crawford, and J. M. Abbett, "Indivo: a personally controlled health record for health information exchange and communication.," *BMC medical informatics and decision making*, vol. 7, no. 1, p. 25, Jan. 2007.

[139] S. N. Weingart, D. Rind, Z. Tofias, and D. Z. Sands, "Who uses the patient internet portal? The PatientSite experience.," *Journal of the American Medical Informatics Association : JAMIA*, vol. 13, no. 1, pp. 91–5, Jan. 2006.

[140] P. C. Tang, J. S. Ash, D. W. Bates, J. M. Overhage, and D. Z. Sands, "Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption.," *Journal of the American Medical Informatics Association : JAMIA*, vol. 13, no. 2, pp. 121–6, Jan. 2006.

[141] L. S. Liu, P. C. Shih, and G. R. Hayes, "Barriers to the adoption and use of personal health record systems," in *Proceedings of the 2011 iConference*, New York, New York, USA: ACM, Feb. 2011, pp. 363–370, ISBN: 1450301215.

[142] M. S. Goel, T. L. Brown, A. Williams, A. J. Cooper, R. Hasnain-Wynia, and D. W. Baker, "Patient reported barriers to enrolling in a patient portal.," *Journal of the American Medical Informatics Association : JAMIA*, vol. 18 Suppl 1, no. Supplement 1, pp. 8–12, Dec. 2011.

[143] E. Wartella, V. Rideout, H. Zupancic, L. Beaudoin-Ryan, and A. Lauricella, "Teens, Health, and Technology. A National Survey," *Center on Media and Human Development, School of Communication, Northwestern University*, 2015.

[144] U. Lakshmi, M. Hong, and L. Wilcox, "Integrating Patient-Generated Observations of Daily Living into Pediatric Cancer Care: A Formative User Interface Design Study," in *Proceedings - 2018 IEEE International Conference on Healthcare Informatics, ICHI 2018*, IEEE, Jun. 2018, pp. 265–275, ISBN: 9781538653777.

[145] B. Hill, S. Perri-Moore, J. Kuang, B. E. Bray, L. Ngo, A. Doig, and Q. Zeng-Treitler, "Automated pictographic illustration of discharge instructions with Glyph: impact on patient recall and satisfaction," *Journal of the American Medical Informatics Association*, vol. 23, no. 6, pp. 1136–1142, Nov. 2016.

[146] P. S. Houts, C. C. Doak, L. G. Doak, and M. J. Loscalzo, "The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence," *Patient Education and Counseling*, vol. 61, no. 2, pp. 173–190, May 2006.

[147] G. G. Mayer and M. Michael Villaire, *Health Literacy in Primary Care: A Clinician's Guide*. Springer Publishing Company, 2007, vol. 130.

[148] J. Tack, F. Carbone, L. Holvoet, H. Vanheel, T. Vanuytsel, and A. Vandenberghe, "The use of pictograms improves symptom evaluation by patients with functional dyspepsia," *Alimentary Pharmacology & Therapeutics*, vol. 40, no. 5, n/a–n/a, Jul. 2014.

[149] D. L. Wong and C. M. Baker, "Pain in Children: Comparison of Assessment Scales," *Pediatric Nursing*, vol. 14, no. 1, pp. 9–17, 1988.

[150] J. J. Collins, M. E. Byrnes, I. J. Dunkel, J. Lapin, T. Nadel, H. T. Thaler, T. Polyak, B. Rapkin, and R. K. Portenoy, "The Measurement of Symptoms in Children with Cancer," *Journal of Pain and Symptom Management*, vol. 19, no. 5, pp. 363–377, May 2000.

[151] K. L. Kwekkeboom, "Cancer Symptom Cluster Management," *Seminars in Oncology Nursing*, vol. 32, no. 4, pp. 373–382, Nov. 2016.

[152] Y. Chen, V. Ngo, and S. Y. Park, "Caring for Caregivers: Designing for Integrality," in *Proceedings of the 2013 conference on Computer Supported Cooperative Work*, ACM, 2013, pp. 91–102, ISBN: 1450313310.

[153] L. R. Pina, S.-W. Sien, T. Ward, J. C. Yip, S. A. Munson, J. Fogarty, and J. A. Kientz, "From Personal Informatics to Family Informatics: Understanding Family Practices Around Health Monitoring," in *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, ser. CSCW '17, New York, NY, USA: ACM, 2017, pp. 2300–2315, ISBN: 978-1-4503-4335-0.

[154] F. D. A. Food, "Drug Administration draft guidance for industry on patient-reported outcome measures: use in medical product development to support labeling claims," *Federal Register*, 2006.

[155] H. S. Murthy and W. A. Wood, "The Value of Patient Reported Outcomes and Other Patient-Generated Health Data in Clinical Hematology," *Current Hematologic Malignancy Reports*, vol. 10, no. 3, pp. 213–224, Sep. 2015.

[156] P. West, R. Giordano, M. Van Kleek, and N. Shadbolt, "The Quantified Patient in the Doctor's Office: Challenges & Opportunities," in *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, ser. CHI '16, New York, NY, USA: ACM, 2016, pp. 3066–3078, ISBN: 978-1-4503-3362-7.

[157] X. Liu, L. Liu, S. J. Simske, and J. Liu, "Human Daily Activity Recognition for Healthcare Using Wearable and Visual Sensing Data," in *2016 IEEE International Conference on Healthcare Informatics (ICHI)*, IEEE, Oct. 2016, pp. 24–31, ISBN: 978-1-5090-6117-4.

[158] R. E. Jensen, S. P. Gummerson, and A. E. Chung, "Overview of Patient-Facing Systems in Patient-Reported Outcomes Collection: Focus and Design in Cancer Care," *Journal of Oncology Practice*, vol. 12, no. 10, pp. 873–875, Oct. 2016.

[159] M. K. Hong, C. Feustel, M. Agnihotri, M. Silverman, S. F. Simoneaux, and L. Wilcox, "Supporting Families in Reviewing and Communicating about Radiology Imaging Studies," in *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, vol. 2017-May, New York, New York, USA: ACM Press, 2017, pp. 5245–5256, ISBN: 9781450346559.

[160] T. Ni, A. K. Karlson, and D. Wigdor, "AnatOnMe," in *Proceedings of the 2011 annual conference on Human factors in computing systems - CHI '11*, New York, New York, USA: ACM Press, 2011, p. 3333, ISBN: 9781450302289.

[161] A. Jang, D. L. MacLean, J. Heer, A. Jang, D. L. MacLean, and J. Heer, "BodyDiagrams," in *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14*, New York: ACM Press, 2014, pp. 1153–1162, ISBN: 9781450324731.

[162] M. K. Hong, U. Lakshmi, K. Do, S. Prahalad, T. Olson, R. I. Arriaga, and L. Wilcox, "Using Diaries to Probe the Illness Experiences of Adolescent Patients and Parental Caregivers," in *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, ser. CHI '20, Association for Computing Machinery, 2020, 1–16, ISBN: 9781450367080.

[163] A.-M. Rosland, "Sharing the Care: The Role of Family in Chronic Illness," California Healthcare Foundation, Tech. Rep., 2009.

[164] N. Yamashita, H. Kuzuoka, T. Kudo, K. Hirata, E. Aramaki, and K. Hattori, "How Information Sharing about Care Recipients by Family Caregivers Impacts Family Communication," in *Proceedings of the 2018 CHI Conference on Human Factors*

in Computing Systems - CHI '18, New York, New York, USA: ACM Press, 2018, pp. 1–13, ISBN: 9781450356206.

[165] T. Toscos, K. Connelly, and Y. Rogers, "Best Intentions: Health Monitoring Technology and Children," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, ACM, 2012, pp. 1431–1440, ISBN: 145031015X.

[166] S. J. Gentles, C. Lokker, and K. A. McKibbon, "Health Information Technology to Facilitate Communication Involving Health Care Providers, Caregivers, and Pediatric Patients: A Scoping Review," *Journal of Medical Internet Research*, vol. 12, no. 2, e22, 2010.

[167] A. Grimes, D. Tan, and D. Morris, "Toward Technologies that Support Family Reflections on Health," in *Proceedinfs of the ACM 2009 international conference on Supporting group work - GROUP '09*, New York, New York, USA: ACM Press, 2009, p. 311, ISBN: 9781605585000.

[168] C. L. Schaefbauer, D. U. Khan, A. Le, G. Sczechowski, and K. A. Siek, "Snack Buddy: Supporting Healthy Snacking in Low Socioeconomic Status Families," in *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing - CSCW '15*, New York, New York, USA: ACM Press, 2015, pp. 1045–1057, ISBN: 9781450329224.

[169] K. Lukoff, T. Li, Y. Zhuang, and B. Y. Lim, "TableChat: Mobile Food Journaling to Facilitate Family Support for Healthy Eating," *Proceedings of the ACM on Human-Computer Interaction*, vol. 2, no. CSCW, pp. 1–28, Nov. 2018.

[170] J. Y. Shin, J. Kedroske, R. Vue, R. Sankaran, D. Chaar, T. Churay, and S. W. Choi, "Design Considerations for Family-centered Health Management: Preliminary Findings with Pediatric BMT Patients," in *Proceedings of the 17th ACM Conference on Interaction Design and Children*, ser. IDC '18, New York, NY, USA: ACM, 2018, pp. 593–598, ISBN: 978-1-4503-5152-2.

[171] B. Gaver, T. Dunne, and E. Pacenti, "Design: Cultural Probes," *interactions*, vol. 6, no. 1, pp. 21–29, 1999.

[172] K. Boehner, J. Vertesi, P. Sengers, and P. Dourish, "How HCI interprets the probes," in *Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '07*, New York, New York, USA: ACM Press, 2007, p. 1077, ISBN: 9781595935939.

[173] N. Bolger, A. Davis, and E. Rafaeli, "Diary Methods: Capturing Life as It Is Lived," *Annual review of psychology*, vol. 54, no. 1, pp. 579–616, 2003.

[174] F. Cordeiro, E. Bales, E. Cherry, and J. Fogarty, "Rethinking the Mobile Food Journal: Exploring Opportunities for Lightweight Photo-Based Capture," in *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, New York, New York, USA: ACM Press, 2015, pp. 3207–3216, ISBN: 9781450331456.

[175] A. Ståhl, K. Höök, M. Svensson, A. S. Taylor, and M. Combetto, "Experiencing the Affective Diary," *Personal and Ubiquitous Computing*, vol. 13, no. 5, pp. 365–378, Jun. 2009.

[176] N. Gorm and I. Shklovski, "Participant Driven Photo Elicitation for Understanding Activity Tracking: Benefits and Limitations," in *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, ser. CSCW '17, New York, NY, USA: ACM, 2017, pp. 1350–1361, ISBN: 978-1-4503-4335-0.

[177] R. Gouveia, E. Karapanos, and M. Hassenzahl, "Activity Tracking in Vivo," in *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, ser. CHI '18, New York, NY, USA: ACM, 2018, 362:1–362:13, ISBN: 978-1-4503-5620-6.

[178] A. Cherenshchykova and A. D. Miller, "Family-Based Sleep Technologies: Opportunities and Challenges," in *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, ser. CHI EA '19, New York, NY, USA: ACM, 2019, LBW1718:1–LBW1718:6, ISBN: 978-1-4503-5971-9.

[179] J. Binda, E. Georgieva, Y. Yang, F. Gui, J. Beck, and J. M. Carroll, "PhamilyHealth: A Photo Sharing System for Intergenerational Family Collaboration on Health," in *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing*, ser. CSCW '18, New York, NY, USA: ACM, 2018, pp. 337–340, ISBN: 978-1-4503-6018-0.

[180] V. Braun and V. Clarke, "Using Thematic Analysis in Psychology," *Qualitative research in psychology*, vol. 3, no. 2, pp. 77–101, 2006.

[181] M. Sharko, L. Wilcox, M. K. Hong, and J. S. Ancker, "Variability in Adolescent Portal Privacy Features: How the Unique Privacy Needs of the Adolescent Patient Create a Complex Decision-Making Process," *Journal of the American Medical Informatics Association*, vol. 25, no. 8, pp. 1008–1017, Aug. 2018.

[182] J. S. Ancker, M. Sharko, M. Hong, H. Mitchell, and L. Wilcox, "Should Parents See Their Teen's Medical Record? Asking About the Effect on Adolescent–Doctor Communication Changes Attitudes," *Journal of the American Medical Informatics Association*, vol. 25, no. 12, pp. 1593–1599, Dec. 2018.

[183] C. Elsden, A. C. Durrant, D. Chatting, and D. S. Kirk, "Designing Documentary Informatics," in *Proceedings of the 2017 Conference on Designing Interactive Systems - DIS '17*, New York, New York, USA: ACM Press, 2017, pp. 649–661, ISBN: 9781450349222.

[184] S. Amershi, K. Inkpen, J. Teevan, R. Kikin-Gil, E. Horvitz, D. Weld, M. Vorvoreanu, A. Fourney, B. Nushi, P. Collisson, J. Suh, S. Iqbal, and P. N. Bennett, "Guidelines for Human-AI Interaction," in *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, New York, New York, USA: ACM Press, 2019, pp. 1–13, ISBN: 9781450359702.

[185] J. Nielsen and R. Molich, "Heuristic evaluation of user interfaces," in *Conference on Human Factors in Computing Systems - Proceedings*, New York, New York, USA: Association for Computing Machinery, Mar. 1990, pp. 249–256, ISBN: 0201509326.

[186] S. Choudhury, S.-J. Blakemore, and T. Charman, "Social Cognitive Development During Adolescence," *Social cognitive and affective neuroscience*, vol. 1, no. 3, pp. 165–74, Dec. 2006.

[187] D. M. Reddy, R. Fleming, and C. Swain, "Effect of Mandatory Parental Notification on Adolescent Girls' Use of Sexual Health Care Services," *JAMA*, vol. 288, no. 6, pp. 710–714, Aug. 2002.

[188] E. Kaziunas, A. G. Buyuktur, J. Jones, S. W. Choi, D. A. Hanauer, and M. S. Ackerman, *Transition and Reflection in the Use of Health Information: The Case of Pediatric Bone Marrow Transplant Caregivers*, 2015.

[189] *What is a Serious Adverse Event? — FDA*.

[190] J. A. Manganello, R. F. DeVellis, T. C. Davis, and C. Schottler-Thal, "Development of the Health Literacy Assessment Scale for Adolescents (HAS-A)," *Journal of Communication in Healthcare*, vol. 8, no. 3, pp. 172–184, Jul. 2015.

[191] K Lorig, A Stewart, P Ritter, V González, D Laurent, and J Lynch, *Stanford Chronic Disease Self-Management Study in Psychometrics reported in Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996.

[192] J. W. Varni, T. M. Burwinkle, E. R. Katz, K. Meeske, and P. Dickinson, "The PedsQL™ in pediatric cancer," *Cancer*, vol. 94, no. 7, pp. 2090–2106, Mar. 2002.

[193] J. W. Varni, M. Seid, T. Smith Knight, T. Burwinkle, J. Brown, and I. S. Szer, "The PedsQL in pediatric rheumatology: Reliability, validity, and responsiveness of the

Pediatric Quality of Life Inventory? generic core scales and rheumatology module," *Arthritis & Rheumatism*, vol. 46, no. 3, pp. 714–725, Mar. 2002.

[194] T. R. Nansel, A. J. Rovner, D. Haynie, R. J. Iannotti, B. Simons-Morton, T. Wysocki, B. Anderson, J. Weissberg-Benchell, and L. Laffel, "Development and Validation of the Collaborative Parent Involvement Scale for Youths with Type 1 Diabetes," *Journal of pediatric psychology*, vol. 34, no. 1, pp. 30–40, 2009.

[195] M. J. Bonner, K. K. Hardy, A. B. Guill, C. McLaughlin, H. Schweitzer, and K. Carter, "Development and Validation of the Parent Experience of Child Illness," *Journal of Pediatric Psychology*, vol. 31, no. 3, pp. 310–321, Apr. 2006.

[196] A. Bandura, "Guide for constructing self-efficacy scales," *Self-efficacy beliefs of adolescents*, vol. 5, no. 1, pp. 307–337, 2006.

[197] E. Basch, D. Artz, D. Dulko, K. Scher, P. Sabbatini, M. Hensley, N. Mitra, J. Speakman, M. Mccabe, and D. Schrag, "Patient Online Self-Reporting of Toxicity Symptoms During Chemotherapy," *J Clin Oncol*, vol. 23, no. 15, pp. 3552–3561, May 2005.

[198] K. E. Heron, R. S. Everhart, S. M. McHale, and J. M. Smyth, "Systematic Review: Using Mobile-Technology-Based Ecological Momentary Assessment (EMA) Methods with Youth: A Systematic Review and Recommendations.," *Journal of Pediatric Psychology*, vol. 33, pp. 358–367, May 2017.

[199] A. A. Stone, S. Shiffman, J. E. Schwartz, J. E. Broderick, and M. R. Hufford, "Patient compliance with paper and electronic diaries," *Controlled Clinical Trials*, vol. 24, no. 2, pp. 182–199, Apr. 2003.

[200] S. D. Horner and A. Brown, "An exploration of parent-child dyadic asthma management influences on quality of life.," *Issues in comprehensive pediatric nursing*, vol. 38, no. 2, pp. 85–104, Jun. 2015.

[201] D. A. Kenny, D. A. Kashy, and W. L. Cook, *Dyadic Data Analysis*. Guilford press, 2006.

[202] Genetic Alliance and Family Voices, "Children and Youth with Special Healthcare Needs, Then and Now," 2013.

[203] C.-F. Chung, K. Dew, A. M. Cole, J. Zia, J. A. Fogarty, J. A. Kientz, and S. A. Munson, "Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data," in *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing - CSCW '16*, New York, New York, USA: ACM Press, 2016, pp. 768–784, ISBN: 9781450335928.

[204] B. DiSalvo and P. Khanipour Roshan, "Medium Probes: Exploring the Medium not the Message," in *Proceedings of the 2014 conference on Designing interactive systems - DIS '14*, New York, New York, USA: ACM Press, 2014, pp. 239–248, ISBN: 9781450329026.

[205] G. Rosti, "Role of narrative-based medicine in proper patient assessment," *Supportive Care in Cancer*, vol. 25, no. Suppl 1, pp. 3–6, Apr. 2017.

[206] M. S. Cepeda, C. R. Chapman, N. Miranda, R. Sanchez, C. H. Rodriguez, A. E. Restrepo, L. M. Ferrer, R. A. Linares, and D. B. Carr, "Emotional Disclosure Through Patient Narrative May Improve Pain and Well-Being: Results of a Randomized Controlled Trial in Patients with Cancer Pain," *Journal of Pain and Symptom Management*, vol. 35, no. 6, pp. 623–631, Jun. 2008.

[207] N. Singh Ospina, K. A. Phillips, R. Rodriguez-Gutierrez, A. Castaneda-Guarderas, M. R. Gionfriddo, M. E. Branda, and V. M. Montori, "Eliciting the Patient's Agenda-Secondary Analysis of Recorded Clinical Encounters," *Journal of General Internal Medicine*, vol. 34, no. 1, pp. 36–40, Jan. 2019.

[208] P. S. Hinds, M. Hockenberry-Eaton, E. Gilger, N. Kline, C. Burleson, S. Bottomley, and A. Quargnenti, "Comparing patient, parent, and staff descriptions of fatigue in pediatric oncology patients," *Cancer nursing*, vol. 22, no. 4, pp. 277–289, 1999.

[209] I. N. Olver, J. A. Eliott, and B. Koczwara, "A qualitative study investigating chemotherapy-induced nausea as a symptom cluster," *Supportive Care in Cancer*, vol. 22, no. 10, pp. 2749–2756, Oct. 2014.

[210] K. Lohse, N. Shirzad, A. Verster, N. Hodges, and H. F. M. Van der Loos, "Video Games and Rehabilitation: Using Design Principles to Enhance Engagement in Physical Therapy," *Journal of Neurologic Physical Therapy*, vol. 37, no. 4, pp. 166–175, Dec. 2013.

[211] L. Uttley, A. Scope, M. Stevenson, A. Rawdin, E. T. Buck, A. Sutton, J. Stevens, E. Kaltenthaler, K. Dent-Brown, and C. Wood, "Clinical effectiveness of art therapy: quantitative systematic review," 2015.

[212] *Chapter Four: How parents and schools regulate teens' mobile phones — Pew Research Center*.

[213] *How Teens and Parents Navigate Screen Time and Device Distractions — Pew Research Center*.

[214] J. O. Wobbrock and J. A. Kientz, "Research Contributions in Human-Computer Interaction," *interactions*, vol. 23, no. 3, pp. 38–44, Apr. 2016.